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ABSTRACT

Four conference papers discuss past research and suggest future research on severe vision impairment and blindness in the elderly. Aspects considered include statistical and psychological implications, service needs, and the social and cultural context of aging in American society. Each paper is followed by a discussion. A final discussion and a concluding comment are provided, along with the agenda and lists of invitees. (JD)



PROCEEDINGS OF THE RESEARCH CONFERENCE ON GERIATRIC BLINDNESS AND SEVERE VISUAL IMPAIRMENT



ERIC

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Proceedings of the Research Conference on Geriatric Blindness and Severe Visual Impairment

September 7-8, 1967

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE OFFICE OF EDUCATION

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American Foundation for the Blind 1968

FOREWORD

The research-oriented Conference on Aging was held September 7-8, 1967, at the Mayflower Hotel in Washington, D. C. For some time, we had had inquiries from researchers about the population of aged blind persons, who comprise, after all, the majority of the blind and severely visually impaired. In attempting to answer these queries, it became increasingly clear to us that much must be learned of these people: their number, their social characteristics, their place in society, and the responsibilities of the service delivery system toward them.

The result of the conference is this proceedings volume. It lays before the researcher and the practitioner alike the problems of the aged blind and sets the problems within the context of our knowledge about them. As it turns out, we do not know very much, and possibly because our knowledge of them is so limited, we have raised many more questions than we have settled.

It is also clear that we have further need for two more conferences: one devoted to settling the questions raised by researchers, and another devoted to the implications for practice of the considerations of the participants in this volume.

We are pleased to have had this opportunity to open for discussion the impensely important problems associated with identification of this population and the equally important problems of the delivery of services to them.

The conference itself was supported in part through a grant from the Administration on Aging of the Department of Health, Education, and Welfare, No. AA-4-67-046-01. The Proceedings were prepared for publication by the International Research Information Service of the American Foundation for the Blind.

M. R. Barnett
Executive Director
American Foundation for the Blind, Inc



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ERIC*

PROCEEDINGS OF THE RESEARCH CONFERENCE ON GERIATRIC BLINDNESS AND SEVERE VISUAL IMPAIRMENT

INTRODUCTION

Eric Josephson, Chairman

My role in the conference whose proceedings are published here was not a precisely defined one; I felt somewhat like the statesman who said: "I am their leader, therefore I follow them." A few remarks may, however, set the stage for what follows.

First, this was a research conference. Hence it dealt with research done in the past, and with research that we believe should be done in the future. And, considering the participants, we were also interested in the implications of present and future research for policy and for action regarding the status and welfare of elderly blind people.

We have dealt here with a very serious social and medical problem, one that has been neglected in research on aging, one that has been neglected in research on blindness, and one that has certainly been neglected in our institutional arrangements for the elderly blind. Yet, although it is easy to fall prey to a rather gloomy—even a pessimistic—approach, it is important that we neither exaggerate the problematic aspects of geriatric blindness, nor underestimate its seriousness. Not all elderly blind people are helpless, and certainly not all of them are pathological.

It is easy to fall into the trap of assuming that the stigma of blindness is greater than in fact it is. Some of the data I have collected suggest that blindness is not feared as much as the literature often says it is; and there is some evidence of a change in attitudes toward blindness. A recent nationwide survey found, for example, that far from being the most dreaded disease, blindness was fairly far down on the list--after cancer. Although half the persons interviewed consider cancer the most terrible of all diseases, less than a fifth had the same feeling about blindness. So, too, in a comparison of survey data collected in 1938 and in 1965, I found evidence that fear of blindness has decreased rather sharply: the idea that "blindness is a fate worse than death" is much less prevalent today than thirty years ago. These are just clues, but it is possible that we are living in a period of change, a period of transition regarding this impairment.

I might also say, parenthetically, that there is some evidence of change in attitudes toward old age itself. It is reflected in social legislation such as Medicare. And it may also be reflected in such things as the significant drop in suicide rates among the aged during the last ten or twelve years. Thus, the suicide rate for white males of sixty-five and older has dropped measurably during this period, while the rate among young Negro males has increased very significantly during the same period. If these clues suggest anything, it is that attitudes about the status of blind persons and old persons are changing. We should be alert to the directions of change.



The problem of status deserves another comment. We are aware that many elderly blind people suffer from other impairments and other chronic conditions. One of our responsibilities will be to assess the relative saliency of the several conditions that afflict people in old age. My own study of several years ago showed that blind people who suffered from other chronic conditions were less likely to consider themselves blind than those who were blind with no other chronic conditions. Again, the older a person, the less likely he was to regard himself as blind. What is invloved in these cases has been described by sociologists as the intervening variables between the individual and his accommodation to, or his "adjustment" to, his impairment. We are not talking about simply an elderly blind person; we are talking about old, blind persons who have differing physical characteristics, differing health characteristics, differing ethnic and socioeconomic characteristics. Each one of these is a complex of events, conditions, circumstances that affects in profound ways the reaction of a person to his family and friends, and their reaction to him. Another way to put the point is to ask about the salience of blindness to the elderly person; or, conversely, the saliency of old age to the blind.

Finally, a comment on "disengagement" among the elderly. Elaborate theories of disengagement have been developed in the literature on aging. I should like to suggest that, although there is doubtless a certain process of disengagement—at least in the social sense—among many elderly people, this process actually may begin before old age. How could we explain otherwise some of the data that show how active many elderly blind people are, despite a multiplicity of impairments and handicaps? There seem to be several populations. At one extreme, there are those who are probably active all their lives; they are very much "engaged," and remain so, despite the onset of blindness. At the other extreme, there are those who may have been withdrawn or withdrawing earlier in life, whether or not they are blind.

These are but some of the issues one could raise in this context. Some are treated implicitly, some explicitly, in the papers that follow. And even with the broadest possible view of changes in status, and the broadest possible sociological and psychological approach to the combination of conditions discussed above, in all honesty we must admit that there is much our society has to do in social policy and in welfare. One need only read the relevant passages in the works of Jules Henry or Peter Townsend to get an idea of some of the ways in which our society dehumanizes institution lized elderly people.

It is our hope that the following papers will open up some of these areas for discussion, for research, and possibly for implementation of social policy.

STATISTICAL IMPLICATIONS OF THE PROBLEM OF GERIATRIC SEVERE VISION IMPAIRMENT AND BLINDNESS

Hyman Goldstein*

Shakespeare conceived the seven ages of man as ending "sans teeth, sans eyes, sans taste, sans everything." If the prosaic license of interpreting "sans eyes" may be used by this writer to represent the usual definition of economic blindness in this country (of a visual acuity of 20/200 or less in the better eye), and if Shakespeare's seventh age may be defined as "sixty-five and over," then it might be interesting to determine to what extent Shakespeare's picture of the visionless seventh age appears to be approaching reality.

Any assessment of the statistical implications or magnitude of a public health problem must be based on solid data dealing with incidence and prevalence. One of the real difficulties in writing a paper in this area is the fact that there are no solid data on incidence and prevalence of economic blindness available for the country as a whole. †

However, types of data are available, each with its own limitations:

1. Estimates are available. The latest estimate (for 1965) for prevalence is 416,400, and for incidence 32,700 (4).

However, even with the assumption that the base from which estimates are made (one state register for prevalence and two state registers for incidence) is representative (which it is not) and of sufficient size (which it is not), there is no guarantee that the assumptions are appropriate. The errors of estimate, unfortunately, remain unknown.

2. Data are available on reported incidence and prevalence of economic blindness from a number of states in this country, known as the Model Reporting Area for Blindness Statistics (MRA), in existence since 1962 and comprising about 19 percent of the population (9).

However, since the states in this area are not considered representative of the country either geographically or demographically, and especially with respect to the inclusion of ethnic groups, such data must be used with great caution. Furthermore,

*The author was formerly Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness, National Institutes of Health. His opinions are his own and do not reflect any area of interest of the Children's Bureau.

†Economic blindness is defined as visual acuity of 20/200 or less in the better eye with best correction, or visual acuity of more than 20/200 if the widest diameter of the field of vision subtends an angle no greater than 20° .



it is not known to what degree cases of blindness are underreported to registers in this area and how the nonreported vary by age, sex, race, degree of vision loss, and cause. Finally, there is no information on the completeness with which these registers are cleared of those who no longer should be on such registers.

3. Surveys by the National Center for Health Statistics have been of two types. One, based on interview of respondents, does not include data secured by examination. It is obvious that a respondent will usually have no accurate information concerning the degree of loss or diagnosis and etiology of his own visual impairment, not to mention those of immediate relatives. The other, based on actual visual examination of randomly selected persons, would offer some hope of securing nationwide data. However, of necessity, the samples tested have been small and are thus beset with rather large sampling errors. In addition, the visual testing has failed to include measurement of field of vision or assessment of visual acuity with best correction.

With these limitations in mind, this paper will be concerned with utilizing available data to arrive at some picture of the statistical implications of the problems of geriatric severe vision impairment and blindness.

Estimates of Economic Blindness

During the period 1940 to 1960, the general population increased by 36 percent, or roughly about one third. It has been estimated that the prevalence of economic blindness increased by some 67 percent, or roughly two thirds. This increase thus was about twice as great as the increase in the population at large. It would be informative, however, to determine whether specific age groups in the general population are increasing at faster or slower rates than similar age groups among the blind. Again, for the latter, only estimates are available for the country as a whole during the twenty-year period. It is noted that while the under-20 age group in the general population showed an increase of 51.6 percent, it was estimated that it increased 253.7 percent among the blind (probably due in large part to the increased incidence of retrolental fibroplasia); for the 20-to-64 group in the general population, an increase of 20.8 percent; and among the blind, an estimated increase of 54.0 percent. However, in the 65-and-older group the general population increased by 83.3 percent, but the same age group among the blind increased by only 61.7 percent. (See Table 1.)

Table 1

Census Population and Estimated Prevalence of Economic Blindness by Age Group with Percent Change: United States, 1940 to 1960

		Population usands)	<u>!</u>		Estimated Prevalence of Economic Blindness				
Age (in years)	1940	1960	Percent Change	1940	1960	Percent Change			
All ages	132,165	179,323	+35.7	230,300	385,000	+ 67.2			
Under 20	45,511	69,005	+51.6	10,800	38,200	+253.7			
20-64	77,617	93,757	+20.8	107,300	165,270	+ 54.0			
65 and over	9,036	16,560	+83.3	112,200	181,450	+ 61.7			
Referen	ce· (4)								

This may be shown also by a comparison of the percent changes in estimated blindness prevalence rates by age group from 1940 to 1960. (See Table 2.)

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Table 2

Estimated Economic Blindness Prevalence Rates per 100,000 Population by Age Group with Percent Change: United States, 1940 to 1960

Ī	Rate per 100,	000 Populatio	<u>on</u>
years)	1940	1960	Percent Change
	174.9	213.9	+ 22.2
0	23.8	55.1	+131.5
	138.7	175.6	+ 26.6
ver	1,244.2	1,095.9	- 11.9
ver 4).	1,244.2	1,095.9	

Although the over-all prevalence rate increased by some 22 percent, the rate per 100,000 for those 65 and over decreased by about 12 percent, from 1,244.2 in 1940 to 1,095.9 in 1960. If such decrease is true, it may be due to one or more of the following causes: (1) a decreased incidence rate, possibly due to the effects of (a) medical advances in preventing ocular disorders from progressing to blindness, (b) preventive measures, such as safety glasses, legislative control over sale of fireworks, and the like; (2) decreased duration of blindness possibly due to increased sight restoration rates or to decreased survival rates among the blind; (3) increased numbers of diagnosed cases not reported to registers and/or; (4) increased numbers of undiagnosed blind persons. These possible causes will be reviewed one by one.

A comparison of the percent changes in estimated incidence of blindness rates by age groups from 1940 to 1960 is shown in Table 3.

Table 3

Estimated Economic Blindness Incidence Rates per 100,000 Population by Age Group with Percent Change: United States, 1940 to 1960

v V	Rate per 100,0	00 Populati	on
Age (in years)	1940	1960	Percent Change
All ages	13,3	16.8	+ 26.3
Under 20	1.9	6.0	+215.8
20-64	9.2	11.5	+ 25.0
65 and over	106.0	92.0	- 13,2

The estimated incidence rate per 100,000 for the age group 65 and over decreased about 13 percent over the 20-year period—from 106.0 in 1940 to 92.0 in 1960. This drop occurred despite the fact that the other age groups showed substantial percent increases in their estimated incidence rates.

Concerning sight-restoration rates, mention must be made of a recent study of 11,732 individuals registered as blind in Massachusetts over a twenty-year period



(1940 to 1960), who were traced to determine survival status and blindness status as of December 31, 1961 (5). The study revealed that the probability of restored sight in the age group 65 years and over is quite low (1 to 4 percent), except for those blind as a result of cataracts. The chances are that, in general, sight-restoration rates in this age group have always been quite low. The same study indicated that in the age group 65 to 74 years the chances of dying within ten years from diabetes, vascular lesions, heart disease, and general arteriosclerosis (including hypertension, diseases of arteries, and other diseases of the circulatory system) were higher for the blind than for the general population. This, of course, resulted in decreased survival rates. However, at age 75 and over, little difference was apparent in survivorship between the two groups, except, perhaps, with respect to diabetes. It is interesting to note that the prevalence rate of economic blindness due to diabetes has been estimated to have increased from 2.4 per 100,000 in 1940 to 23.9 in 1960, an increase of almost 900 percent; in similar fashion, the blindness prevalence rate due to vascular diseases has been estimated to have increased over 300 percent in the same period (4). Unless medical breakthroughs occur, it does not appear likely that decreases in incidence rates of blindness due to diabetes or vascular diseases are apt to occur in the foreseeable future. It should be mentioned again that this study of survivorship and causes of death among the blind covered the period 1940 to 1960. It was not possible, by the nature of the study and the size of the study group, to determine whether there were trends in survivorship or changes in the pattern of causes of death during the period. Attempts to compare the data with a study by an insurance company of its industrial policy holders throughout the country covering the period 1923 to 1933 did not prove fruitful because of differences in definition of blindness, differences in geographic coverage, and other differences (2).

Reported prevalence rates, like reported incidence rates, depend on a report being made available for statistical purposes. A diagnosed case of blindness is not and cannot become a statistic until this occurs. Blindness due to cataract is most amenable to sight restoration, provided the cataract is removed. However, it has been shown recently that the aged cataract patient is often resistant to the suggestion of surgery (3). Physicians failing to report blindness due to cataract, on the assumption that it is "temporary" blindness until the patient decides to undergo surgery, are responsible for a considerable proportion of unreported cases. It is obvious that the failure of the physicians or other eye examiners to report a case, regardless of whether such reporting is mandatory, results in understatements of reported incidence and prevalence. Even a delay in reporting, harmless as that seems, may distort trend data significantly. Mention has not been made of blind persons who are not diagnosed as blind even upon examination. The number of such false negatives is unknown, and can only be revealed by studies designed with such an objective.

Nonreporting starts with nonexamination. A blind person who is unaware that he needs ocular examination and treatment, or who is unwilling or unable to secure such care, represents another statistic that may never come to light. It would appear likely that because of advanced age and financial condition, the population 65 years and over is apt to be well represented among the undiagnosed blind. The number and distribution of such persons can be determined by surveys designed to screen scientifically selected populations. No information is available in this country concerning the degree of completeness of reporting of diagnosed blind persons to official blindness registers, or the perhaps more important matter of the proportion of undiagnosed blind persons. Thus, it is not possible to determine whether there has been any change over the years in completeness of reporting of diagnosed blind persons or in the proportion of undiagnosed blind persons. These are two important gaps in our knowledge that need attention and exploration.

From this analysis, it is obvious, I believe, that the data needed to interpret the decrease in estimated blindness prevalence rate from 1940 to 1960 are not available. The need for factual information on trends in incidence and prevalence of economic blindness, duration of blindness, survivorship, and sight restoration among the blind is most urgent.

Reported Economic Blindness

We referred in the last section to the recent development of the MRA. At present it encompases some fourteen states, covering about one fifth of the population of the United States. There are no data available to show to what degree those that should be reported by eye examiners are actually being reported, or to what degree those on the register who should be removed from the register because of death, sight restoration, or nonresidence are actually being removed. These are factors that can, in the first case, make for understatement of incidence and prevalence, and in the latter case make for overstatement of incidence and prevalence.

Data from the MRA have been available and published for four years (1962 through 1965, inclusive). Cause data have been available for three years. The short life of the area makes it impossible to detect meaningful trend information. The MRA states, by virtue of the self-selection underlying their interest in and desire for MRA membership, and their major concentration on the East Coast, are not representative of the country with respect to demographic, geographic, ethnic group, white/nonwhite, or urban/rural distributions. However, while meaningful incidence or prevalence data may not yet be available and while the determination of trends depends on the passage of years, it may be possible to use the available data for clues as to relationships between geriatric blindness and other factors.

The 1965 MRA data, based on thirteen states, showed a marked increase in rate with age, reaching a reported incidence rate of 40.4 per 100,000 in the 65-to-74 age group (which was about double that of the preceding age group, 45 to 64) (8). ("Age," here, refers to age of registrant in 1965, not age at onset of blindness.) The rate then tripled to 131.4 in the 75-to-84 age group, and then more than doubled to reach its peak of 316.8 in the age group 85 and over. There were higher rates for males than for females below 65 years, and a reversal of such differences at age 65 and over when the female rates, in general, were higher.

The rate per 100,000 for nonwhite persons (96.8) in the 65-to-74 age group was about three times that of whites (33.2); in the 75-to-84 age group, that for nonwhite persons (22.0) was about twice that of white persons (116.9). It is not possible to compare rates in the 85-and-older age group because the estimated population of nonwhite persons in this group in the MRA states in 1965 was less than the minimum of 25,000 persons considered necessary as a base for the computation of meaningful rates.

Males aged 65 and over accounted for 41.0 percent of all newly reported male blind persons; for females, it was 55.0 percent. Whether this is a reflection of the greater reported incidence rate per 100,000 in females (88.0) than is the case in males (73.7) for the 65-and-over age group, or whether it is a reflection of greater life expectancy of females, is not known.

White persons aged 65 and over accounted for 52.2 percent of all reported incidence in 1965 for white persons, as compared to 35.9 percent in the similar case for nonwhite persons, probably reflecting the fact that in MRA states the percent of persons aged 65 and over of the total white population was about one-half times that for persons aged 65 years and over in the total nonwhite population, according to the 1960 decennial census.

The distribution of degree of vision for newly reported economic blind aged 65 years and over does not differ essentially from that for those under 65 years.



Table 4 shows rates of first additions to the register per million for the age group under 65 years and for that 65 years and over for known major affection groups in 1965 for thirteen MRA states.

Table 4

First Additions to Register by Known Age and Known Major Affection Groups^a:

MRA Total, b 1965 (number and rate)

				Ma	jor A	ffectio	n Gro	upsc	····	·		-	
Age (in yrs.)	Total (known affec- tions)	Glaucoma Other Than Congenital	Myopia	Keratitis	Other Affections of Cornea or Sclera	Gt	Uveitis	Retrolental	rioropiasia Retinal De- generation	Other Retinal Affections	Optic Nerve Atrophy	Multiple Affec-	All Others
Number													
Total, all agesd	4,712	524	130	49	95	1,061	193	48	843	673	282	323	491
Under 65	2,426	187	108	29	58	407	150	48	269	436	238	81	415
65 and over	2,286	337	22	20	37	654	43	pm 2013	574	237	44	242	76
				Rate	per l	Million	Popu	latio	<u>n</u>				
Total, all ages ^d	130.7	14.5	3.6	1.3	2.6	29.4	5.3	1.3	23.4	18.7	7.8	9.0	13.6
Under 65	73.8	5.7	3.3	0.9	1.8	12.4	4.6	1.5	8.2	13.3	6.9	2.5	12.6
65 and over	712.1	105.0	6.9	6.2	11.5	203.7	13.4		178.8	73.8	13.7	75.4	23.7

Reference: (8).

 $^{^{\}mathrm{a}}\mathrm{Data}$ limited to first additions examined by ophthalmologists and eye-ear-nose-throat specialists.

bExclusive of South Dakota.

^cStandard Classification of Causes of Severe Vision Impairment and Blindness, 1965 Revision.

dExcluding unknown age.

It is noted that in every major affection group, except retrolental fibroplasia, the rate for those 65 and over exceeds that for those under 65. In the case of retinal degeneration, the rate for the older blind group is about 22 times that of the younger; for glaucoma, about 18 times as great, and for cataract about 16 times as great.

Table 5 shows similar rates per million for known etiology groups in 1965 for thirteen MRA states for first additions in the under-65 age group and for that 65 and over.

Table 5

First Additions to Register by Known Age and Known Major Etiology Groups^a: MRA Total, ^b 1965 (number and rate)

Age (in known years) Total (known etiologies) I of the property of the pro	Major Etiology Groups ^C											
Total, all agesd 3.524 104 154 70 525 825 139 71 733 228 675 Under 65 1,893 85 142 64 356 115 45 62 691 53 280 65 and over 1,631 19 12 6 169 710 94 9 42 175 395 Rate per Million Population Total, all agesd 97.7 2.9 4.3 1.9 14.6 22.9 3.9 2.0 20.3 6.3 18.7		(known	Infectious Diseases	Injuries, Poisonings	Neoplasms	Diabetes	Senile De- generation	Vascular Diseases		Prenatal Influence	Multiple Etiologies	Unknown to Science
agesd 3.524 104 154 70 525 825 139 71 733 228 675 Under 65 1,893 85 142 64 356 115 45 62 691 53 280 65 and over 1,631 19 12 6 169 710 94 9 42 175 395 Rate per Million Population Total, all agesd 97.7 2.9 4.3 1.9 14.6 22.9 3.9 2.0 20.3 6.3 18.7					<u>N</u>	lumber	•					•
65 and over 1,631 19 12 6 169 710 94 9 42 175 395 Rate per Million Population Total, all agesd 97.7 2.9 4.3 1.9 14.6 22.9 3.9 2.0 20.3 6.3 18.7	4	3,524	104	154	70	525	825	139	71	733	228	675
Rate per Million Population Total, all agesd 97.7 2.9 4.3 1.9 14.6 22.9 3.9 2.0 20.3 6.3 18.7	Under 65	1,893	85	142	64	356	115	45	62	691	53	280
Total, all agesd 97.7 2.9 4.3 1.9 14.6 22.9 3.9 2.0 20.3 6.3 18.7	65 and over	1,631	19	12	6	169	710	94	9	42	175	395
agesd 97.7 2.9 4.3 1.9 14.6 22.9 3.9 2.0 20.3 6.3 18.7	Rate per Million Population											
Under 65 57.6 2.6 4.3 1.9 10.8 3.5 1.4 1.9 21.0 1.6 8.5	₹	97.7	2.9	4.3	1.9	14.6	22.9	3.9	2.0	20, 3	6.3	18.7
	Under 65	57.6	2.6	4.3	1.9	10.8	3.5	1.4	1.9	21.0	1.6	8,5
65 and over 508.1 5.9 3.7 1.9 52.6 221.2 29.3 2.8 13.1 54.5 123.1	65 and over	508.1	5.9	3.7	1.9	52.6	221.2	29.3	2.8	13.1	54.5	123.1

Reference: (8).

^aData limited to first additions examined by ophthalmologists and eye-ear-nose-throat specialists.

bExclusive of South Dakota.

^cStandard Classification of Causes of Severe Vision Impairment and Blindness, 1965 Revision.

dExcluding unknown age.

With the exception of prenatal influence, injuries and poisonings, and neoplasms, the rate for the older group exceeds that of the younger. The rate for senile degeneration for the older group is about 63 times that for the younger. In similar fashion, the

rate for vascular diseases for the older group is 21 times, and that for etiology "unknown to science" 14 times, that of the younger group. The high ratio of the rates for the older blind to the younger blind for multiple affections and multiple etiologies may be explained by the fact that often an older person is diagnosed as blind quite some time after the onset of his disability. The physician may be confronted with a blind person, long post facto, with several ocular conditions, but with an incomplete or inadequate supporting history. He may find it difficult under such circumstances to determine the primary affection and primary etiology of the blindness. The high incidence among the aged of glaucoma and cataract, for which the etiology is unknown, probably accounts for the high ratio of rates due to etiology "unknown to science" of older persons to younger ones.

Functional Visual Impairment

Some workers in the field of blindness believe that it is more important and meaningful to measure visual functioning and efficiency than merely distance visual acuity alone. Such functioning is dependent, of course, not only upon visual measures of various types, but upon auditory, intellectual, motor, and motivational factors, among others. The interindividual variability in operation of such factors may in large part explain the great variation in mobility and communication exhibited by blind persons having the same degree of visual loss. An interview survey of vision impairment was conducted by the National Health Survey of persons 6 and older in the United States during the period from July, 1963 to June, 1964. It was based on household interviews of the civilian, noninstitutional population, and used a questionnaire dealing with visual functioning developed under contract with Dr. Milton D. Graham of the American Foundation for the Blind. Each respondent was asked these three questions, among others: "Can you see well enough to read ordinary newspaper print with glasses?" "Can you see well enough to recognize the features of people you know if they are close enough?" "Can you see objects that move, such as cars moving or people walking?" Where a respondent answered "No" to all three questions he was asked a supplementary set of questions of which the first was: "Can you see well enough to tell if a light is on or off?" The other questions in the supplement related to the respondent's history of visual impairment, such as type of onset (that is, suddenly, gradually, or at birth); age at onset; use of aids in mobility and communication; recreation and educational pursuits; special vocational training; occupation; and so on. It should be mentioned that those respondents who answered "No" to any, but not all, of the first three questions, were asked a somewhat different supplementary set of questions.

Preliminary unpublished data and rates of vision impairment are now available from this survey (7). One must remember that these prevalence rates are not comparable to prevalence rates derived by use of the economic definition of blindness most widely used in this country, which is based on actual examination which, in turn, is based solely on measurement of central visual acuity with best correction, or of field of vision.

Table 6 shows prevalence rates per 1,000 for those individuals who have both eyes involved.

Omitted from this table are data for those who could see newprint and who, at the same time, had no trouble or hardly any trouble seeing. The rate per 1,000 for all ages (that is, 6 and older) was 7.6; for those 6 through 64 years, 2.7; and for those 65 years and over, 49.4.

Table 6

Rate per 1,000 Population of Degree of Vision Impairment of Persons 6 and over with Both Eyes Involved by Age: United States,
July, 1963 to June, 1964

	R	Rate per 1,000 Population							
	Both Sexes All Ages	Age	(in years)						
	(6+)	6-64	65 and over						
Total	7.6	2.7	49.4						
Cannot see newsprint	6.0	2.0	39.9						
Cannot see features, moving objects or light	0.4	1)						
Cannot see features, moving objects, can see light	0.5	0.6	5.0						
Can see features or moving objects	1.0		7.2						
Can see both features and moving objects	4.2	1,5	27.7						
Can see newsprint ^a	1.6	0.7	9.5						
Cannot see features and/or moving objects or has great			r						
deal of trouble seeing	0.9	0.7	4.9						
Some trouble seeing	0.7)	4.6						

Reference: (7).

^aIncludes unknown degree of impairment.

In order to interpret these findings and to determine, if possible, which visual measures (such as near and distance visual acuity, field of vision, depth perception, color perception, binocularity, and so forth), as well as factors other than vision, are most closely correlated with visual functioning, ophthalmological and other examinations of a representative sample of persons with various types of functional visual impairments are necessary. An ophthalmological examination would also be helpful in determining whether specific affections and etiologies are related to specific functional impairments.

Although the rates based on functional impairment are not comparable to those based on the economic definition of blindness, or on any definition based solely on distance visual acuity or field of vision, it is possible to compare the ratio of the prevalence rate of the 65-and-older group to that of the under-65 group. Table 7 shows such age rate comparisons for estimated binocular blindness prevalence rates per 1,000 population in 1960 for the United States, for reported binocular blindness prevalence rates for the MRA states in 1965, and for functional binocular vision impairment prevalence rates for the United States in 1963/64.

Table 7

Rate per 1,000 Population of (a) United States Estimated Binocular Blindness Prevalence, 1960; (b) MRA Reported Binocular Blindness Prevalence, 1965; and (c) United States Binocular Vision Impairment Prevalence, 1963 to 1964, by Age

	Rate per 1,000	Rate per 1,000 Population							
Age (in years)	U.S. Estimated Binocular Blindness ^a Prevalence, 1960	MRA Reported Bi- nocular Blindness ^b Prevalence, 1965	U.S. Vision Impairment ^C Prevalence, 1963/64						
Under 65	1.3	0.9	2.7 ^d						
65 and over	10.9	7.3	49.4						
Ratio 65 and over rat Under 65 rate	e 8.4	8. 1	18.3 ^e						

References: (4, 7, 8).

The ratios for those based solely on visual acuity or an equally disabling loss in the field of vision and derived from register data are fairly close: 8.4 for the United States in 1960, and 8.1 for the MRA states in 1965. However, the ratio of older to younger functional impairment rates for the United States in 1963/64 was 18.3. This great increase over the ratios mentioned is largely due to a great increase in the prevalence rate for the older group. The ratio of 18.3 is no doubt understated, because the rate for the younger group (2.7 per 1,000) covers the age span 6 through 64 years. If it had also included the under-6 group, the younger rate would have been lower.

These findings would seem to indicate that functional impairment is not only relatively more frequent in the older group than in the younger group, but to a greater degree than is the case when distance visual acuity or peripheral field of vision is the sole criterion, for example, in economic blindness.

Predictions of Prevalence and Incidence

It has been indicated that it is not possible to pinpoint specific reasons for the decline in estimated prevalence rate for the 65-and-over group from 1940 to 1960 in this country. At the present time there appears to be no evidence that the rate is



^aBased on estimate projected from combined data of blindness registers of three states, using definition of economic blindness.

bBased on register data from fourteen MRA states using definition of economic blindness.

^cBased on household interviews of random sample of civilian, uninstitutional population with definition of vision impairment based on inability to see any or all of the following: newsprint, features, moving objects, or light, or on some trouble in seeing.

dThis is the rate for the 6-to-64 age group.

eThis ratio is understated because the rate for the younger group, excluding all those under 6, is greater than would be the case if those under 6 had been included.

either decreasing or increasing. Knowing what we do, inadequate as that may be, what can we predict?

For the 65-and-over age group there has been estimated a blindness prevalence rate for 1960 for the United States as a whole of 1,095.9 per 100,000 (4). If it is assumed that the rate has not varied since 1960 and will not vary significantly from this level for the next eighteen years, then, with a projected United States population aged 65 years and over in 1985 of 25,006,000, the bleak picture of approximately 274,000 blind persons 65 and over looms large (6). This projected army of the aged blind is greater in size than the combined 1960 census of the total populations of Battle Creek, Michigan, Salem, Oregon, Topeka, Kansas, and White Plains, New York.

The estimated incidence rate for 1960 for the United States was 92.0 per 100,000 for the 65-and-over age group (4). Assuming that there has been no significant increase or decrease in this rate since 1960, and that it will remain at that level at least until 1985, it would be expected that with an estimated population of 25,006,000 in the 65-and-over age group in 1985, there would be 23,006 newly reported blind persons in that age group alone. This may be compared with an estimated 15,230 such persons in 1960 (4).

These projections assume no significant change in prevalence or incidence rate from now until 1985. This is predicted on an assumption that there will be no medical breakthroughs to reach etiologies that now elude science, and that no new and unforeseen ocular disorders appear on the horizon. However, what would happen if a liberalization of the definition of severe vision impairment and blindness were to take place?

To answer this question it is better to compare rates based on different definitions, but derived from the same population at risk, rather than to use different and possibly noncomparable populations.

The effect of a change in definition on incidence was believed by the author to be more important than the effect on prevalence, since incidence more accurately reflects the influence on vision impairment of current environmental and other factors than does prevalence. It is recognized that the newly reported blind are not always the newly blind. To that extent reported incidence includes an unknown proportion of previously unreported incidence.

Table 8 shows rates of first additions to MRA registers in 1965 on the basis of definitions where the degree-of-vision criteria of severe vision impairment are respectively 20/200 or less, 10/200 or less, 5/200 or less, and absolute blindness, for the age groups under 65 and 65 and over. Included in the table are the percent losses of central vision corresponding to the various levels of visual acuity (1).

It is obvious from the data that as the definition is made more and more restrictive, there is relatively greater exclusion of the older blind than of the younger blind.

Figure 1 plots the data of Table 8 on semilog paper. Semilog paper is appropriate for graphing rates of change of series of data that are quite dissimilar in magnitude. Thus, it is quite suitable for plotting the rates of change of first addition rates for those persons under 65, and for those 65 and over subjected to different definitions of blindness. The abscissa shows the percent loss of central vision that corresponds to the visual acuity notations used (1). It is noted that a visual acuity of 20/200 corresponds to an 80 percent loss of central vision. The curves for the two age groups are projected by freehand in Figure 1 to a visual acuity of 20/160, which



corresponds to a 70 percent loss of central vision, and hence could be the basis of a more liberal definition. In general, although the rates of the two age groups are of considerably different magnitude, the rates of change are quite similar. If the definition of severe vision impairment, concerned with eligibility for benefits and services, were to be changed to include a visual acuity of 20/160 or less, then the projected rate for the 65-and-over age group would be approximately 95 per 100,000. If this rate is applied to the projected population in 1985 of 25,006,000 aged 65 and over, there would be anticipated in that age group a population of almost 24,000 persons newly added to blindness registers in that year (6). In view of the fact that this projection is based on register data and thus probably represents incompletely reported incidence, it should be considered an absolute minimum.

Rates of First Additions to Register per 100,000 Population by Known Age Group and by Known Degree of Vision (with equivalent percent loss of central vision): MRA Total, a 1965

		Rate per 100	,000 Population			
Degree of Vision	Percent Loss of Central Vision	Under 65	65 and over 77.0			
20/200 or less ^b	80	7.7	77.0			
10/200 or less ^b	90	5.4	55.2			
$5/200 \text{ or less}^{\mathbf{b}}$	95	4.0	40.9			
Absolute blindness	100	0.7	4.0			

Reference: (1, 8).

Table 9 shows the effect of change in definition on rates of first additions per 100,000 of white and nonwhite persons 65 and over in MRA states in 1965.

The rates for nonwhite persons are two to three times those for white persons. A more restrictive definition appears to be associated with a relatively greater decrease in reported incidence among white persons.

Figure 2 shows the data of Table 9.

It would seem that the projected first addition rate for white persons 65 and over, with an economic blindness definition based on a visual acuity of 20/160 or less, would predict a rate of approximately 85 per 100,000; that for nonwhite persons, 180 per 100,000.

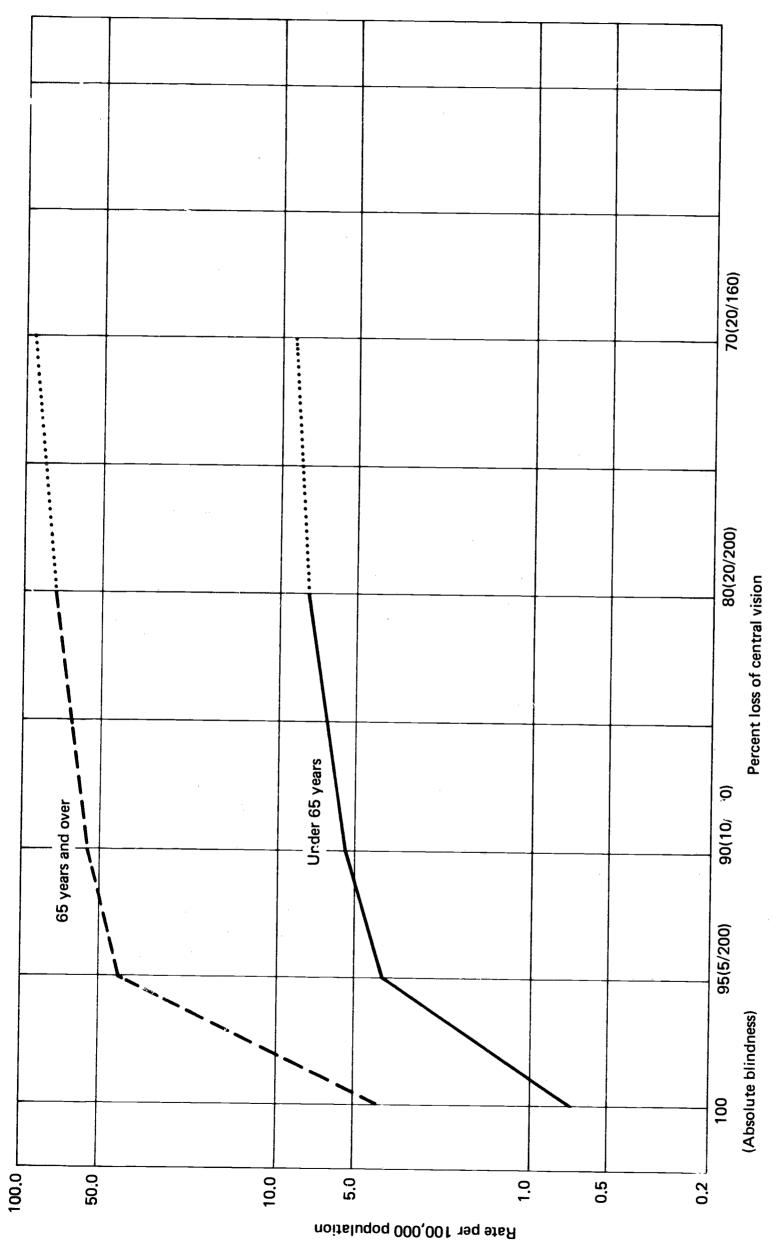
Table 10 indicates that the first addition rates of females 65 and over are slightly higher than those for males of the same age group.

A change of definition affects the sexes to approximately the same degree.

Figure 3 plots the data of Table 10.

^aExclusive of South Dakota.

bIncludes cases of field restriction.



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Figure 1. Rates per 100,000 Population of First Additions to Blindness Register by Known Age Group and by Percent Loss of Central Vision with Projection to Visual Acuity of 20/160: MRA States, 1965

With an economic blindness definition based on a visual acuity of 20/160 or less the predicted rate for males is 85 per 100,000; for females, 110 per 100,000.

Table 9

Rates of First Additions, 65 and over, to Register per 100,000

Population by Known Race and by Known Degree of Vision (with equivalent percent loss of central vision): MRA Total, a 1965

		Rate per 100,000 Population				
Degree of Vision	Percent Loss of Central Vision	White	Nonwhite			
20/200 or lessb	80	67.5	136.5			
$10/200 \text{ or less}^{\text{b}}$	90	47.7	103.3			
$5/200 \text{ or less}^{\mathbf{b}}$	95	34.1	87.8			
Absolute blindness	100	3.1	11.4			

References: (1, 8).

aExclusive of South Dakota.

bIncludes cases of field restriction.

Table 11 indicates the changes in percent of known major affection groups resulting from changes in definition in the younger and older groups.

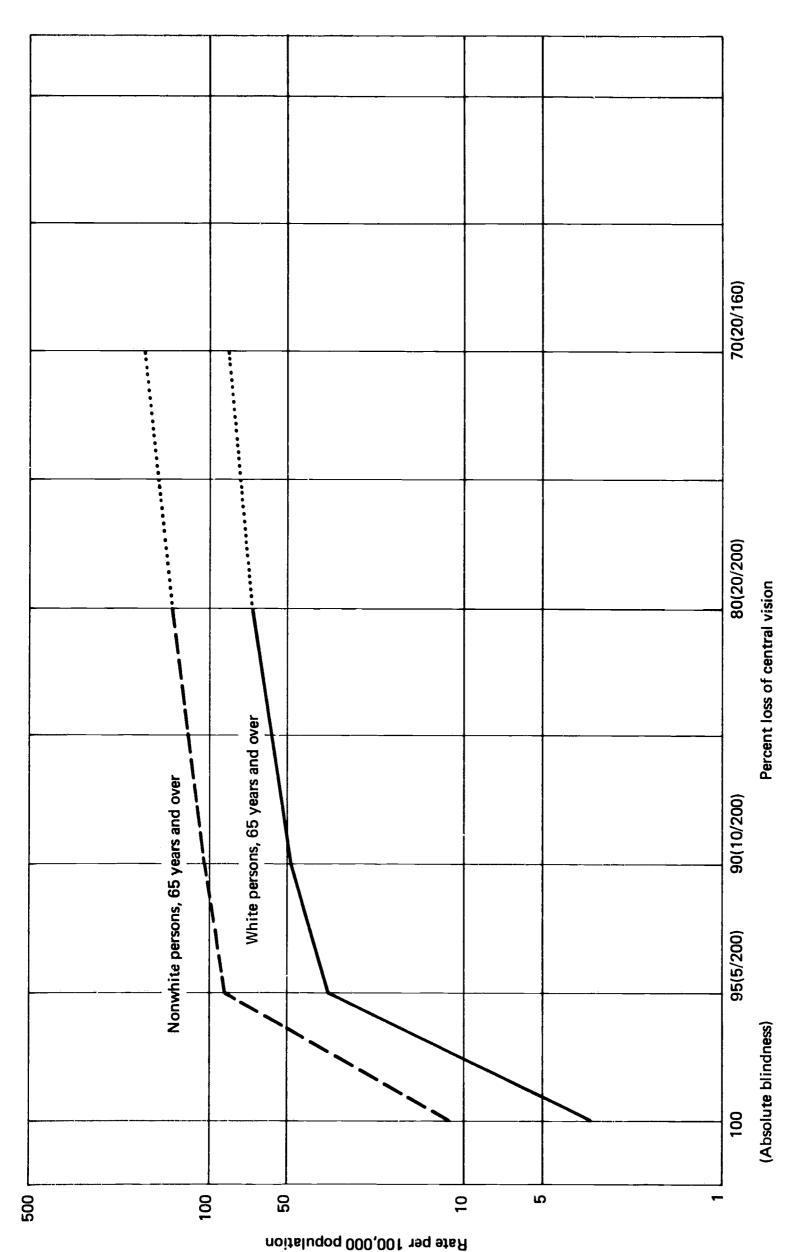
Restricting the definition to absolute blindness results in greatly diminished percents of first additions with cataract or retinal degeneration in the 65-and-over age group, and in greatly increased percents of such additions with glaucoma or optic nerve atrophy. It may be presumed that liberalizing the definition beyond 20/200 might reverse the changes noted.

In Table 12 the effect of changes in definition on percent distribution of known major etiology groups among first additions to MRA registers in 1965 under 65 and 65 and over is noted.

Restricting the definition to absolute blindness appears to result in a decrease in percent of such additions where the etiology is senile degeneration or diabetes. However, the etiology groups of vascular diseases and "unknown to science" show major increases in percent. Again, it may be presumed that extending the definition beyond 20/200 might tend to reverse these changes.

It can be noted from the above that a change in definition not only affects incidence and prevalence, as expected, but also changes the composition of the reported economically blind group by age, race, affection, and etiology. This emphasizes how risky it is to compare distributions of such variables between studies with different definitions.





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Rates per 100,000 Population of First Additions, 65 and over, to Blindness Register by Known Race and by Percent Loss of Central Vision with Projection to Visual Acuity of 20/160: MRA States, 1965 Figure 2.

Table 10 Rates of First Additions, 65 and over, to Register per 100,000 Population by Known Sex and by Known Degree of Vision (with equivalent percent loss of central vision): MRA Total, a 1965

The second secon	with the state of	Rate per 10	0,000 Population
Degree of Vision	Percent Loss of Central Vision	Male	Female
20/200 or lessb	80	69.7	82.8
10/200 or less ^b	90	52.0	57.7
5/200 or less ^b	95	38.9	42.5
Absolute blindness	100	3.8	4.2

References: (1, 8).

aExclusive of South Dakota.

bIncludes cases of field restriction.

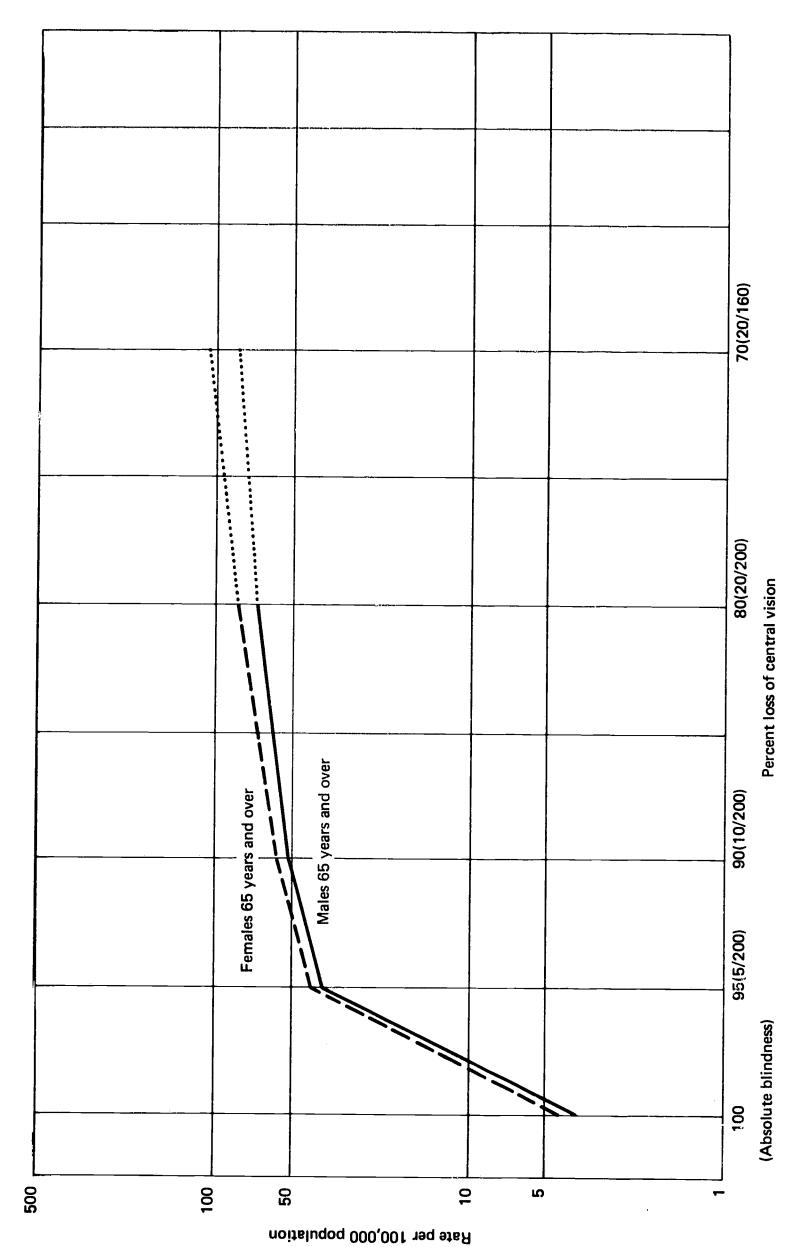
Table 11 First Additions to Register Cumulated by Known Degree of Vision, Known Major Affection Groups, and Known Age: MRA Total, a 1965 (percent)

Major Affection Groups (percent)											
Age and Degree of Vision	Number of Cases	Total	Glaucoma	Myopia	Keratitis	Cataract	Uveitis	Retrolental Fibroplasia	Retinal Degeneration	Optic Nerve Atrophy	All Others
Under 65 years 20/200 or less ^b	2,302	100.0	7.8	4.4	1.3	16.4	6.2	1.9	11.3	9.7	41.0
$10/200 \; \mathrm{or} \; \mathrm{less}^{\mathrm{b}}$	1,593	100.0	9,0	2.5	1.2	15.3	6.1	2.1	11.2	10.2	42.3
$5/200 \; \mathrm{or} \; \mathrm{less}^{\mathrm{b}}$	1,197	100.0	10.9	1.5	1.1	14.5	5.7	2.7	10.5	10.5	42.7
Absolute blindness	176	100.0	6.8	0.6	1.7	4.5	4.5	6.8	2.8	13.6	58.5
65 and over $20/200$ or less	2,21 9	100.0	14.6	0.9	0.9	28.5	1.8	0	25.4	1.9	25.9
$10/200 \; \mathrm{or} \; \mathrm{less}^{\mathrm{b}}$	1,576	100.0	16.2	0.7	0.7	28.0	1.9	0	24.2	2.3	25.8
$5/200$ or $less^b$	1,165	100.0	18.2	0.6	1.0	28.7	2.1	0	20.9	2.3	26.3
Absolute blindness	89	100.0	37.1	1.1	3.4	14.6	1.1	0	5.6	10.1	27.0

Reference: (8).

^aExclusive of South Dakota. ^bIncludes cases of field restriction.





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Rates per 100,000 Population of First Additions, 65 and over, to Blindness Register by Known Sex and by Percent Loss of Central Vision with Projection to Visual Acuity of 20/160: MRA States, 1965 Figure 3.

Table 12

First Additions to Register Cumulated by Known Degree of Vision,
Known Major Etiology Groups,^a and Known Age: MRA Total,^b 1965 (percent)

Age and Degree of Vision It It It It It It It I	Major Etiology Groups (percent)												
$\begin{array}{c ccccccccccccccccccccccccccccccccccc$			Total	Infectious Diseases	Injuries, Poisonings	Neoplasms	Diabetes	Senile De- generation	Vascular Diseases	Gen	Prenatal Influence	l .	All Others
5/200 or less ^c 960 100.0 4.3 10.5 5.2 22.5 4.9 3.0 3.6 27.1 15.9 2.9 Absolute blindness 156 100.0 1.9 28.2 14.1 11.5 0.6 0.6 3.9 28.9 8.3 1.9 65 and over 20/200 or less ^c 1,584 100.0 1.2 0.7 0.3 10.5 43.8 5.9 0.5 2.5 23.9 10.6 10/200 or less ^c 1,128 100.0 1.3 0.8 0.3 10.4 42.6 6.1 0.5 2.6 25.3 10.0 5/200 or less ^c 833 100.0 1.3 0.7 0.2 10.3 39.5 6.6 0.7 2.6 28.0 10.0		1,784	100.0	4.1	7.5	3.5	19.5	6.4	2.3	3.3	35.4	15.1	2.9
Absolute blindness 156 100.0 1.9 28.2 14.1 11.5 0.6 0.6 3.9 28.9 8.3 1.9 10/200 or less ^c 1,584 100.0 1.2 0.7 0.3 10.5 43.8 5.9 0.5 2.5 23.9 10.6 10/200 or less ^c 1,128 100.0 1.3 0.8 0.3 10.4 42.6 6.1 0.5 2.6 25.3 10.0 1.5 200 or less ^c 833 100.0 1.3 0.7 0.2 10.3 39.5 6.6 0.7 2.6 28.0 10.0 1.	$10/200 \; \mathrm{or} \; \mathrm{less}^{\mathrm{c}}$	1,259	100.0	4.1	8.5	4.6	22.5	5.5	2.8	3.7	29.6	15.3	3.4
65 and over 20/200 or less ^c 1,584 100.0 1.2 0.7 0.3 10.5 43.8 5.9 0.5 2.5 23.9 10.6 10/200 or less ^c 1,128 100.0 1.3 0.8 0.3 10.4 42.6 6.1 0.5 2.6 25.3 10.0 5/200 or less ^c 833 100.0 1.3 0.7 0.2 10.3 39.5 6.6 0.7 2.6 28.0 10.0	$5/200 ext{ or less}^{\mathbf{c}}$	960	100.0	4.3	10.5	5.2	22.5	4.9	3.0	3.6	27.1	15.9	2.9
20/200 or less ^c 1,584 100.0 1.2 0.7 0.3 10.5 43.8 5.9 0.5 2.5 23.9 10.6 10/200 or less ^c 10/200 or less ^c 1,128 100.0 1.3 0.8 0.3 10.4 42.6 6.1 0.5 2.6 25.3 10.0 1.3 0.7 0.2 10.3 39.5 6.6 0.7 2.6 28.0 10.0 10.0 1.3 0.7 0.2 10.3 10.5 10.	Absolute blindness	156	100.0	1.9	28.2	14.1	11.5	0.6	0.6	3.9	28.9	8.3	1.9
5/200 or less ^c 833 100.0 1.3 0.7 0.2 10.3 39.5 6.6 0.7 2.6 28.0 10.0	4	1,584	100.0	1.2	0.7	0.3	10.5	43.8	5.9	0.5	2.5	23.9	10.6
	$10/200~ m or~less^{C}$	1,128	100.0	1.3	0.8	0.3	10.4	42.6	6.1	0.5	2.6	25.3	10.0
	$5/200 \; \mathrm{or} \; \mathrm{less}^{\mathrm{c}}$	833	100.0	1.3	0.7	0.2	10.3	39.5	6.6	0.7	2.6	28.0	10.0
Absolute blindness 64 100.0 1.6 1.6 3.1 7.8 7.8 14.1 1.6 6.3 54.7 1.6	Absolute blindness	64	100.0	1.6	1.6	3.1	7.8	7.8	14.1	1.6	6.3	54.7	1.6

Reference: (8).

aIncluding etiology "unknown to science."

bExclusive of South Dakota.

^cIncludes cases of field restriction.

Discussion

Although estimated prevalence rates of economic blindness for the 65-and-over age group seems to indicate a decrease of some 12 percent in such rates from 1940 to 1960, there is no assurance that such a decrease has actually occurred, because of the rather limited base from which estimates have been made. Attempts to determine whether other types of data, such as sight restoration rates, survival rates, and so on could shed some light on the matter of trends and prevalence rates proved futile, because of the unavailability of such data based on similar definitions of blindness and for comparable geographic and demographic groups over a period of years, so that trends could be determined.

If needed data are to be based on registers or reporting systems, then the requirement of a common definition of blindness, standard procedures to measure the degree of completeness of reporting and updating, and the use of a standard classification of causes of severe vision impairment and blindness are obvious. That studies are needed on a periodic basis to determine sight restoration and survival rates among the blind goes without saying.



Program planning needs the type of information that can help pinpoint the nature and number of services and facilities needed for the blind in the years ahead. Such information can only be derived from systems of uniform data collection that are routine, that can periodically assess the reliability of the data, and that are flexible enough to meet special needs for special types of data as such needs occur.

Reported incidence and prevalence leave unanswered the major questions concerning the number of blind that are either undiagnosed or, if diagnosed, unreported. The magnitude of the undiagnosed cases may well represent the portion of the 'iceberg' that is beneath the surface, particularly among the aged, depending on financial condition, the number and availability of examining resources, and other factors. The unreported blind represent a loss to the blind in terms of services that could be made available; they are also a loss to society in its attempts to get a better picture of the problem.

Data from 1965 from the Model Reporting Area for Blindness Statistics, although understated because of incomplete reporting, showed that reported incidence rates rose steeply with advancing age, regardless of sex, with rates for nonwhite persons being about two to three times those of white persons, particularly among the aged populations. In every major affection group (except retrolental fibroplasia) the rates for the 65-and-over group exceeded that for those under 65. The ratio of the rates of the older group to the younger ones for retinal degeneraltion, glaucoma, and cataract were particularly high, ranging from 16 to 22. In the case of major etiology groups, the rates for the older group exceeded those of the younger group (with the exception of prenatal influence, injuries and poisons, and neoplasms), with the rate for senile degeneration in the older group being 63 times that of the younger group; for vascular diseases, 21 times; and for etiology 'unknown to science, " 14 times.

Data on visual functioning derived by interview by the National Health Survey in the period 1963/64 revealed that the prevalence rate for the 65-and-over age group was some 18 times that of the 6-to-64 group, considerably higher than similar ratios of prevalence rates based on the economic definition of blindness. This would indicate that a visually impaired population, so defined on the basis of visual functioning, would be relatively even more weighted with older people than is the situation now, in which the definition is based on visual acuity or peripheral field of vision.

On the basis of the data secured from MRA states in 1965, it would seem that liberalization of the definition of economic blindness (such as including those showing an acuity of 20/160 or less) would no doubt result in relatively greater proportions, of persons 65 and over, than those under 65 being considered severely visually impaired, and thus admitted to registers for such impairment. A liberalization would result in increased percentages of first additions with cataracts or retinal degeneration among the 65-and-over age group, and decreased percentages with glaucoma or optic nerve atrophy. In similar fashion, there would be increases in percentages of first additions to the register in that age group with etiologies due to senile degeneration or diabetes. There would also be decreased percentages of first additions with vascular diseases and those with etiology "unknown to science." Decreased percentages do not necessarily imply decreased numbers when the population at risk is increasing.

It is thus seen that a change in definition not only affects incidence and prevalence, but also the composition of the eligible population in terms of age, race, affection, and etiology.



It would appear that whether the liberalization of the definition of economic blindness is in terms of less severe criteria of visual acuity and field of vision, or in substituting a functional definition for the present one, a greater percent of those so defined would be aged blind.

In view of the fact that there has been some movement to serve those who do not meet the present definition of economic blindness, and in view of the fact that the 65-and-over population (most susceptible of all age groups to severe vision impairments) is increasing at a rapid rate, new responsibilities for serving the visual needs of our senior citizens will no doubt soon be upon us. The necessary planning for these increased responsibilities by agencies concerned should be under way now. We are becoming an older people, and only by our adequacy in meeting these responsibilities can we demonstrate that we also are becoming a wiser people.

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Discussant: Irving D. Goldberg*

15592

I would like to comment on some of the issues covered by Dr. Goldstein, on the thoughts and questions they raise in me, and on their implications as I see them.

If we are going to be concerned with the statistical implications of the geriatric blind and visually impaired, then I think we must first be concerned with the available statistics—in a sense, the state of the statistics. This is precisely what Dr. Goldstein has done in his paper.

I should like to draw your attention first to some of these concerns. One is the quality of the available statistics and the usefulness of these data in meeting the problems that will concern us in this meeting. Dr. Goldstein has mentioned the incidence and prevalence of blindness and severe vision impairment. The available data, he pointed out, are inadequate for making estimates for the United States as a whole. At least they are limited and subject to great error. He referred to the National Health Survey data, the limitations of the NHS interview samples relating to blindness, and the very small numbers involved in the examination surveys which they have conducted. These limitations of the NHS data on examinations are virtually dictated by practical considerations. The bulk of the data on blindness that we use today in this country have come from studies initially done by Dr. Ralph Hurlin, and subsequently from the Model Reporting Area to which Dr. Goldstein referred; and these data are largely, or entirely, based upon the registers of blind persons which the various states around the country maintain. Thus, one has to be concerned with this primary source of data since so many estimates and so many decisions are going to be based on the statistics they produce. Dr. Goldstein pointed out the limitations of these data, the problems of reporting, the effect of delays in reporting among the diagnosed, and the statistical problem of the undiagnosed. I think this concern leads us to emphasize the importance of not relying on a single instrument to tell us what the state of the statistics is with respect to blindness and visual impairment, and specifically with regard to current and future statistics on the geriatric blind.

Now I would like to comment on two aspects which appear to me to be extremely important. One has to do with the undiagnosed, and the other with the diagnosed but unreported.

From some studies, such as those done by Dr. Josephson in Cleveland and elsewhere, there is evidence that the undiagnosed tend to predominate among the aged. So, if we are going to relate the currently available statistics to the problems of aging, then we have to pay careful attention to the potential importance of factors about which we may not have much information. What is the extent of the problem of the undiagnosed blind from the geriatric point of view? I think we must take steps to answer this question. I referred above to the need to rely on more than a single source of data. Possibilities exist, through surveys or other means, to determine the extent to which the reported statistics on blindness and severe vision impairment among the aged understate the total problem because of the exclusion of the undiagnosed group in such statistics.

With respect to underreporting of the diagnosed blind to registers, I think it is important to note Dr. Goldstein's reference to the fact that persons aged 65 and over

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represent the only age group that did not show an increase in blindness prevalence during the 1940-to-1960 period; and also to note that these data were largely based on registers. As some of you know, I was associated with Dr. Goldstein throughout the development of the Model Reporting Area program up until about a year ago, and during that experience I became increasingly aware of the variation in the reported statistics among states, and of the intricacies and problems involved in reporting. One of the aspects was the effect of various state programs on the reported blindness statistics. For example, when Aid to the Blind was the most economically advantageous benefit that a visually impaired person could obtain, the welfare department (or other state agency involved) was able to identify the blind persons through the required ophthalmological or optometric examination. However, when the financial benefits of other new and modified programs (for example, Old Age Assistance, Medical Care for the Aged) exceeded those of the Aid to the Blind in some states, it was advantageous for eligible blind persons to avail themselves of these other opportunities. Eye examinations were not required in those programs and hence not obtained on individuals, who thus did not necessarily become diagnosed as blind, and hence did not become known to the register.

This, then, is an important consideration, and I think if we are going to go further in finding who the blind and visually impaired population are, we have to involve these other agencies. Most, if not all, of these agencies would be concerned with the geriatric population, and hopefully somehow we may be able to obtain ophthalmological examinations on a good part of the population, perhaps after a screening procedure to detect the suspect blind. This may not be as costly as we might anticipate initially, since an effective screening procedure can greatly reduce the number of persons who have to undergo a more costly thorough examination. Dr. Goldstein's experience with the effective use of portable vision testing machines (operated by lay persons) in surveys in Egypt indicates that screening procedures can be feasible on a large scale.

I think we ought to bear in mind, then, such things as the source of the data and the potential for additional information. There is a need for more work on the completeness of reporting of the diagnosed blind, and for more information on the undiagnosed, on the duration of survivorship among the visually impaired, on the effect of various diseases on the problem of blindness, on sight restoration, and so on. What is the relationship between the prevalence of cataracts by age and the age distribution of persons operated on for cataracts? If the incidence of cataracts exceeds the cataract operations among the aged, then this will become an increasingly important problem among the elderly, and early restoration of vision becomes an important concern. This leads to another vital issue or question we have to look into, namely, what are the causes of blindness and what can we do about them?

Parenthetically, I would like to note my disturbance over our free use of the term "blind" in a statistical framework, since that term implies a universally single definition, which of course does not exist. In any event, from blindness data such as those presented by Dr. Goldstein on age, race, sex, and cause of blindness, we can begin to see the patterns that are arising, and to be guided, somewhat at least, in the directions we might take with respect to future work in the area of visual impairment. But I am particularly interested in the emphasis he has given to the question of degree of vision. I think this is one of the most important concerns that we have to consider—more specifically, the question of functional vision. Administrators and researchers (perhaps none more than Dr. Graham) have been aware of this need for some time, but there have invariably been stumbling blocks in the efforts to obtain statistics in this area. How do we measure functional vision? How do we identify the population with special needs because of their limited functional

vision? And, how do we identify the factors that make up functional impairment? Will this aspect be an increasing concern with increasing life expectancy due to the other coexisting medical or physical handicaps among the aged?

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It was apparent from Dr. Goldstein's comments that functional impairment of vision is a relatively much greater problem among the aged than among these under 65 years. It would seem to me, then, that a great deal more emphasis must be placed in the coming years on this particular aspect of measurement of visual impairment, much more than our efforts to date. Somehow, we have to find a means of removing the barriers which have kept us these many years from successfully attacking this problem. We need better data on the extent of the problem of visual impairment so that we can plan better how to meet the needs that arise.

One must ask whether 20/200 is the proper point of demarcation of visual impairment. In this regard I am continually amazed at our consistency in falling into an inevitable trap. In so many publications note is made of the inadequacy of the 20/200 definition. But, having acknowledged this deficiency, we then proceed to develop a project, or discuss a blindness issue, around the 20/200 definition. This path of least resistance may seem to be the only recourse because so much of our available data, so many of our blindness statutes, and so much of our interests are centered at the 20/200 level of vision. This is what dictates our decisions and our direction, and I think we have to exert concerted effort to find some other means by which we can be better guided as to what directions we should take; and this means getting away from the firmness of 20/200, getting deeply involved with the problem of functional vision, and concerning ourselves with related issues requiring resolution. We must begin to think about criteria other than 20/200. I am sure you will agree that this is not the ideal point of demarcation, and certainly not when considering the geriatric population. Breaking down the barriers to a more useful definition or criterion is not easy, as we well know, but I do not think we have exerted sufficient effort in this direction.

The basic issue here is the question of the definition of blindness. We first have to define the problem facing us. What are the problems we are concerned with regarding the geriatric visually impaired? Certainly there is more than a single problem involved, and there is no single approach to the resolution of the problems associated with geriatric blindness and vision impairment. We must give some thought to this issue. Then, in light of these concerns, we have to define what we mean by visual impairment. What are the different needs that will arise and how are we going to get the data we need to answer the questions which arise? This is the general framework which should guide our statistical thinking.

What are some of the other specific questions and issues confronting us? I have referred to the measurement of functional vision and other aspects of degree of vision. What can we do to add to our knowledge in this area through large-scale studies and sample surveys? We should direct some attention to this. How do we identify the undiagnosed blind in the various aid programs that I previously referred to, such as Old Age Assistance? I think we also have to give attention to the effect of age at onset of impairment. This has always been a very difficult thing to measure, and because of this difficulty we have been diverted from paying sufficient attention to the issue, which accounts for the lack of adequate data relating to age at onset. So many people have stated that the age at which a person's vision becomes severely impaired is an important factor which may seriously affect his ability to carry on most efficiently and effectively. What does this mean for the aged? This question certainly requires our attention.

In what direction and to what actions do our statistics lead us? We can become concerned with the various aspects of prevention—primary, secondary, and tertiary. Where shall we direct our efforts?

In primary prevention we are concerned with the occurrence of disease. Should we simply sit back and await the arrival of Dr. Goldstein's "army" of 275,000 geriatric visually impaired persons? And in greeting this army, how are we going to face up to the problems associated with the number and kinds of personnel and facilities which will be required to meet their needs? Or, do we attempt to reduce the size of this army to a mere division by exerting greater efforts toward preventing the occurrence of blindness through the control and prevention of diseases or conditions that lead to visual impairment? This approach was successful with the attack on retrolental fibroplasia. What is the potential for reducing the effect of disbetes and vascular or other diseases which adversely affect vision, particularly as one approaches the older ages? This seems to me to be an extremely important area for us in which to invest our time and energies. Perhaps we should align ourselves more closely with various disease programs, so as to help us determine how to take better advantage of the potential for primary prevention.

In what direction shall we move toward the control of disease, such as early control of glaucoma? Then, what is left for us to do in the form of rehabilitation? What is going to be our load in rehabilitation and what facilities and people will we require to meet these needs? What special problems will this create? What kinds of research do we have to conduct in this regard?

Certainly, we must consider all of these questions and others, so that we can give appropriate attention to every aspect of prevention. Our future efforts should be properly balanced.

In conclusion, it is apparent from Dr. Goldstein's excellent paper that we need a great deal more information than we now have; and we must give more careful attention to the statistics we do have, if we are going to direct our efforts to a more or less balanced program in meeting the problem of geriatric blindness.

Summary of the Goldstein/Goldberg Discussion

The topic of definition of blindness proved, as expected, a lively one. To begin with, the importance of a definition is rather more sociological than statistical, in the sense that the reliability of prevalence, incidence, and trend-pointing depends on how we define visual impairment. Dr. Goldstein was careful to say that the definitions he cited were "economic" definitions of blindness (although they are widely, and incorrectly, called "legal"), and he opined that there would be fewer problems if we restricted the meaning of blindness to total lack of visual perception.

On the other hand, practitioners pointed out the difficulties of identifying what we mean by the effects total blindness. Evidently the functional definition of, or use of, remaining visual powers determines behaviorally whether the person is, or is regarded as, blind. Furthermore, it is difficult to use any current devices to aid in such determination because of the difficulty of establishing benchmarks at the low end of the scale of acuity (whether near or far). Rather than diversifying or liberalizing definitions of blindness, some felt we should encourage the use of multiple definitions: for compensation, for service.



Obviously, having no definition at all would not be desirable: and there seemed to be some concensus that a series of definitions, each serving a different purpose, would be useful. On the matter of device usage in screening for visual impairment, Golstein reported that when the Titmus Optical Screener was used in Egypt by physicians and ophthalmologists trained in its use, very few "false negatives" were picked up; rather, there tended to be an overreferral of false positives, which at least is in the right direction. Retests showed high reliability.

There seemed to be general agreement that there is underreporting of "blindness" in the United States. Yet, in the matter of modifying the number of blind through cataract surgery (a topic on which there is some literature), there is overreporting, in the sense that there is an implication in incidence figures for change which the individuals who have cataracts are not willing to undergo. We come here, again, to the matter of function, and its relation to the services offered the visually impaired individual.

There was some feeling that one of the first steps one could take in defining needs (which apparently would lead back toward definitions for service), is to ask a group of persons becoming both aged and blind to define their needs, and to discuss their functioning. Those involved in the National Health Survey study apparently felt that this was a viable approach, and indeed used it, to an extent, in their own work, at least as far as they could elicit attitudinal data after concluding a formal interview schedule. In those data it was clear that although about three fourths of the respondents in the group of those over 65 years of age admitted limitations of activity, only about a third attributed that limitation to visual impairments; the rest attributed it to other conditions they had along with visual impairment.

From the researcher's point of view, the restrictiveness of a definition of visual impairment depends very much on the amount of money available: if you have sufficient money and can do an elaborate study, you can make the definition as restrictive as one would like. If not much money is available, the sample size must be reduced, or the definition must be loosened.

Also, on the matter of age itself, a simple distinction between those under and those over 65 is, of course, not enough: both groups are too heterogeneous. What is the "point of impact" of visual impairment by age in both groups? Obviously, the meaning of visual impairment, in terms of level of function attained by the individual, in terms of services one could provide him, in terms of the needs he knows about (and the needs he could be informed about), will vary. Intelligent social planning must, indeed, take these matters very seriously into account.

THE SOCIAL AND CULTURAL CONTEXT OF AGING IN AMERICAN SOCIETY

Robert A. Scott

It is a bad strategy, I am told, to start a paper with an apology. Some persons believe that by so doing, one runs the risk of diluting the force of whatever merit may be found in the content and argument of the paper. Worse, such a strategy may make the author appear to be ill informed on his subject, a prospect which should have been more carefully discussed when the plans for presenting the paper were first being negotiated. I acknowledge these hazards, and yet I feel compelled nevertheless to apologize. Indeed, were I not to do so I expect I might be judged guilty of fraud and deception, and properly so. My apology is principally personal, but it is a professional one as well. The personal one stems from the fact that I am attempting in this paper to inform you on a subject about which I can claim no authoritative sociological expertise. I am not a student of the sociology of aging, nor have I had the benefit of any systematic exposure to the full range of social science literature on the subject. My analysis therefore will not be the kind of creative, analytic presentation I would like it to be. The best I can do is to bring to bear on the subject of aging what I hope is a reasonably competent sociological perspective. The paper will consist largely of an attempt to integrate some of the things that other social scientists have had to say on the subject. This brings me to the second aspect of my apology. It stems from what I have found to be the surprisingly incomplete state of social science knowledge about aging in society. I have been struck by how little hard-core scientific data there are concerning the personal and social problems and experiences of those who are the aged in our society, and of any genuine attempt to describe social reality from their point of view. Much of the literature on aging-even some of the best of it—is conjectural. My apology on behalf of the social sciences stems from the rather incomplete status of sociological knowledge about this very important segment of our society.

In one sense, of course, the comparative neglect of this problem is but another manifestation of the more general neglect of the aged in this culture. Our's, of course, is a youth-oriented culture, and many of its most cherished values are associated with youth, hope, and the future. I shall make no attempt to apologize for all of American culture, being content to limit myself to my own discipline and to my training in it. Much of what I have to say here consists of untested hypotheses and educated guesses about what is thought to be the case, rather than of hard-core empirical data concerning what is in fact the case. Having warned the reader of my limitations as well as those of my discipline, my conscience is now clear and I can proceed.

The subject is, of course, the social and cultural context of the aged in American society. Perhaps the first question we need to consider is what the problem of aging has to do with blindness. The answer is a simple one: To a very great degree the problems of blindness are the problems of aging. This fact becomes clear as we review what is known concerning the demographic and social characteristics of the blind in America.





As you may know, estimates of the number of blind persons vary widely from study to study. One report estimates the number at slightly more than 400,000 (1); other studies place the figure at closer to 1,000,000 (2). Despite these rather alarming differences, there is one point on which all studies appear to agree. It is that a majority of persons who are identified as blind, according to the currently accepted administrative definition of that term, are in age groups in which retirement is either imminent or achieved. Hurlin has estimated that nearly 70 percent of all blind persons are 65 or older; and in a recent report by the National Center for Health Statistics, it is estimated that 67 percent of persons classified as blind fall into the age group around 65 (3, 4). These several prevalence estimates of blindness all report that most persons who are blind are elderly. This fact indicates that any effective system of social and welfare services for the blind must be based upon a thorough understanding of the aged in American society. This paper will identify and analyze a number of the salient components of the social and cultural context of the aged in our culture.

One beginning for this analysis is to identify the persons about whom we shall be speaking and to explain why they are becoming the focus of so much special attention. The aged in our society are usually defined as persons 65 or older. At the present time it is estimated that they comprise slightly less than 10 percent of our population, which in terms of numbers amounts to about 19 million persons (5). If we examine the census data of this century, we find that there has been a sharp increase both in the number of elderly persons in our society and in the proportionate contribution their numbers make to the total American population. At the turn of the century, for example, about 4 of every 100 Americans were 65 or older. By 1960, this figure had doubled to 8, and at the present time it is nearly 10. Demographers believe it unlikely that the aged will ever comprise more than 10 percent of the population. On the assumption that they are correct, we can estimate that by 1980 there will be about 24 million older persons in this country, and that by the year 2000 their ranks will probably number 28 million.

This meteoric increase in the number of elderly persons, and in their proportionate contribution to the total population, is a result of certain major advances in medical science and of a sharp increase in the standard of living in our society. Both of these developments have produced a dramatic increase in life expectancy. The increase in the elderly population is not a result of the fact that the human life span has increased, although it has indeed increased slightly since the turn of the century (6). It is rather that the infant mortality rate has been so dramatically reduced by the factors I have mentioned. The result of this decrease is that many more persons than ever now survive childhood to live to old age.

It is not their numbers that make of the elderly a matter of increasing concern to social policy planners in our society. The concern arises when we view their economic, social, and health characteristics in the context of the major social and cultural changes which have been brought about by industrialization. I shall try to touch on some of the salient points about these changes.

When a society industrializes, all of its major social institutions are dramatically affected by the process. One of the social institutions most profundly affected is the family. The reasons for this are as follows. As the economy of a society moves from an agricultural to an industrial base, the place of work customarily shifts from the home to the large factory. In the home all members of the family, including relatives, participate in the production of goods, whereas in the factory only one family member is employed. One consequence of this shift from home to factory is, therefore, that a worker is no longer able to employ a large number of relatives, nor is he able to



earn enough to support any one other than his own immediate family. As a result, the immediate, or nuclear, family comes to replace the large extended family as the primary form of family life.

The nuclear family tends to be small. There are two reasons for this. First, the period of economic dependency of each child on his family lengthens as more training becomes necessary for employment. As this prolonged dependency is a drain on family income, a large family hinders the aspirations of both parents and children to improve their place in the community. Second, in pursuing a career it is necessary for the wage earners to have the freedom to move from one location to another in search of better job opportunities. A large family makes it impossible for him to do so. The nuclear family is also characterized by a reticence, and to some degree even an inability, to incur long-term obligations to groups or persons other than itself. Lasting commitments to parents and relatives mitigate against the family's freedom to move quickly and with a minimum of personal loss.

The consequences of these various changes for older persons are obvious. As their children grow up, they move away from the home communities one at a time, until the parents are finally left by themselves. If they become ill or disabled, their children find it difficult to care for them without incurring unusually high social and economic costs. In effect, the basic family unit is no longer structured to care for its aging members. The fundamental nature of the problems this creates can be appreciated when we examine the health characteristics of the elderly, their economic position, and their ability to continue to $1^{\frac{1}{1-2}}$ independently.

The question of the health status of the aged in American society is, of course, one about which there is currently a tremendous amount of discussion. While many aspects of this question continue to be controversial, there is one very important fact about which there is no disagreement. Among the elderly, chronic and degenerative conditions are the norm rather than the exception. According to one report, about 4 or 5 elderly persons studied suffered from one or more chronic conditions (7). This figure is nearly twice the proportion found in the population as a whole. Many of these conditions apparently create fundamental limitations for the persons who have them. The study found that 45 percent of those over 65 have conditions that in some way limit activities of ordinary living. Most of these limitations were found to be moderately severe. About 15 percent of the elderly persons who were studied reported that their condition prevented them from either working or keeping house; and another 18 percent felt that they were prevented from being as mobile as they wanted to be. These figures indicate that chronic health problems are a normal condition for most aged persons; a state of complete health is a comparative rarity in this segment of the population (8).

Chronic and degenerative diseases affect adjustment to retirement in at least two ways. There is the problem of maintaining some reasonable degree of independence despite the condition; and there is the problem of meeting the costs that result from obtaining necessary medical care. These costs are apparently quite high. One study found that about one of every six elderly persons was hospitalized during any given year; that the average length of hospitalization was twice as long as for younger persons; and that the average costs of the medical care amounted to nearly twice those of younger persons (9). These figures show quite clearly that the health status of the aged, and the costs involved in obtaining adequate medical treatment for them, are two core aspects of the social problem of aging in our society.

Another of the major problems of aging concerns certain social and economic components of retirement. It is the custom in our society for persons to leave the



work force at or near the age of 65. Several assumptions are commonly made about retirement; it is worth examining them in light of recent research. Neugarten has succinctly summarized the 'folk view' of retirement in the following way. 'We commonly assume that most men want to work as long as they possibly can and that retirement is therefore a harmful thing. This argument holds that self-respect is based upon the earning of a living. Without the economic function to perform, a man loses much of the meaning of life, feels worthless, perhaps depressed; in turn, the feelings lead to a decline in physical health" (10). Several of these assumptions are partially or entirely contradicted by the findings of recent studies. In their study of the social meanings of work and retirement, Friedmann and Havighurst found substantial variations in attitude toward retirement between persons who were situated at different places in the occupational prestige structure of the society. They report that in the more prestigeful occupations, the social and psychological meanings of work are almost as important as the economic. As a result, a man's personal identity is intimately connected with his work career. This does not appear to be as true of workers in the lower prestige occupations. For them, work is less involving, so that personal identity is not intimately tied up with employment. They conclude that highly skilled white-collar workers, executives, and professionals are the persons who are most likely of all to have the desire to continue working after the age of 65 (11).

Retirement in our society involves profound changes in an individual's pattern of life. It affects the way in which his time is organized; basic social relationships involving work colleagues are disrupted; fundamental changes occur in the manner of his participation in family and community affairs. How individuals adapt to this event is, of course, determined by their social experiences and personal characteristics. To the average person, however, adjustment to retirement also depends on the amount of income he receives after work stops, and whether any drop in income is perceived by him as a hardship or deprivation.

On the average, of course, most elderly people receive less income than younger persons who are working. Lenore Epstein, in her study of the income of aged persons, found that for two-person families in which both members are over 65, the median income is nearly \$2,900 (12). By comparison, the median income for two-person families under 65 is slightly more than \$5,300, or a difference of about \$2,400. Her study also found that whereas the nonmarried man under 65 has a median income of \$3,371, his counterpart over 65 receives a median income of only \$1,365, a difference of over \$2,000. Nonmarried women under 65 receive a median income of about \$2,150; their counterparts over 65 receive only \$1,015. It is important to keep in mind that the figures for persons under 65 used by Dr. Epstein are based on data for the 1960 census; data for persons over 65 are based on materials collected in 1963. It is reasonable to assume that the median income of persons under 65 increased from 1960 to 1963; as a result, the true differences between these two age groups are probably greater than the ones she has reported.

The amount of income a person receives is, of course, an important measure of his economic status. Perhaps of even greater importance than this, however, is the degree to which this income adequately meets his needs. There are no genuinely reliable measures of the adequacy of income. The United States Bureau of Labor Statistics has attempted to construct a budget that they felt would enable an elderly couple or a single person living in a city to manage an independent household at a modest but adequate standard of living (13). They report that about 72 percent of elderly couples have incomes that enable them to live moderately but adequately. This is true for only 32 percent of single men, and only 17 percent of single women over 65. There is one qualification of this finding. The study assumed that the budget would be adequate for persons who enjoy good health. As we have already shown, this assumption can only be

correctly applied to a minority of older persons. Most of them have at least one chronic or degenerative disorder. As a result, the findings have to be substantially revised in order to take this fact into account.

The exact meaning of these figures, and the issues underlying them, will probably be debated for many years to come. At the moment I believe it is fair to say that the financial position of most elderly people in our society is not a comfortable one. A majority of married couples can manage on their own incomes only if they are in good health; the great majority of single persons, and especially widows, do not have enough income to live independently regardless of the state of their health.

A final aspect of the problems of aging that I want to discuss concerns current living arrangements. According to one study, most older persons continue to maintain their own households (14). In 1960, more than one half of persons over 65 were living independently in their own dwellings. This arrangement is the one most preferred by the persons interviewed and by their children as well. Ethel Shanas has found that older parents generally live near at least one child, and 83 percent of the older persons she interviewed said they preferred their own households. Nearly the same percentage also said they saw their children at least once each week (15).

A key question about the relationships between elderly parents and their adult children concerns the extent to which the former are willing or able to assume responsibility for their parents. Sussman and Shanas have both shown that most adult children expressed a willingness to shoulder these responsibilities (16). They also found that intergenerational ties are strengthened more often than weakened by widowhood, illness, or the onset of extreme old age.

There is one respect in which a long-range shift has occurred in the relations between elders and the current adult generation. The economic support of the aged has been the function not of the family, but of government and economic institutions, through the growth of social security pension plans. Neugarten, in her analysis of the literature on this point, reports finding little evidence that social and emotional ties between parents have lessened in any way (17).

There are two other points I want to discuss. The first concerns the changing character of the geriatric problem in our society; the second concerns the state of our knowledge about the special needs of aged persons who are also blind.

How an individual adjusts to retirement and the nature of the social problem of aging in a society are the joint product of the historical, economic, political, and social characteristics of the times, and of the personal life experience of the individuals who are involved. All of these factors are in a constant state of change; as a result, the personal problems of retirement and the social problem of aging are themselves continually changing as well. Neugarten has captured this point very well; I want to quote from her writings at length. She says: "The persons who now constitute the aged population in the United States are different from those who will follow because the world in which children grow up is constantly changing. People aged 65 or over in 1965 were born for the most part between 1880 and 1900 and grew up during a period of great economic expansion and general optimism in America. Although the frontier had disappeared, its spirit was still prevalent. A lengthy education was the exception rather than the rule; for the average person, formal schooling ended with the eighth grade. Many unskilled jobs existed for youth and for the large numbers of foreigners who came to make a better life in the New World. A young man could get ahead, or so the rags to riches novels of Horatio Alger told him, with persistence, thrift, good manners and morals; and of course a bit of luck. A man expected to work hard and to work



all of his life. If an able-bodied man failed to make a living for his family, it was considered a disgrace and an indication of personality defect. Pension plans and social security did not exist, but if one put aside a bit of money regularly, one presumably would be protected against any illness that might come with old age."

"The people who are old in the 1960s were already adults in the period of rapid technological and industrial change which marked the first half of the twentieth century. In those decades the proportion of agricultural workers dropped from 30 percent to less than 10 percent of all workers, and workskills became subject to rapid obsolescence. Between 1900 and 1935, many Americans lost the conviction that the world was constantly improving. World War I did not make the world safe for democracy, and the Great Depression of the 1930s brought the realization that the individual's economic success or failure did not depend solely on his strength of character. Many of today's aged lost their occupational moorings during the Depression; and, of these, some did not recoup during the period of prosperity ushered in by World War II, nor did they build up sizable equities under the federal security program that developed in the 1940s and 1950s" (18).

In contrast to this picture, succeeding decades will see more and more older people who are native-born Americans. Most of them will have grown up in urban areas and will have enjoyed the advantages of regular medical care during their lifetimes. Almost all of them will have had a high-school education and many of them will have gone to college as well. By the time they reach the current retirement age they will take for granted pension programs, social security, and government assistance programs of all types. The social problem of aging in American society will therefore be different in the years to come from what it is today because the persons who will make it up will have had a vastly different social experience than the one encountered by the current generation of elders. This fact is essential to take into account in any long-range social policy planning.

The final point I wish to make concerns the way in which workers for the blind have viewed the problems of blindness in the aging population. In a recent paper, I analyzed the structure and content of services for the blind in the United States. My conclusions were as follows: "These data show a clear bias in work for the blind in favor of children and employable adults and against elderly blind persons. About 90 percent of agencies in work for the blind place exclusive or primary emphasis upon serving less than one third of the blind population; and only 9 percent of the agencies are seriously concerning themselves with the bulk of the blind persons" (19).

The reasons for the proliferation of services for a limited segment of the blind population are numerous and complex. There is one factor which is, I believe, especially significant in this regard. It concerns the concepts that guide workers for the blind in the day-to-day practice of their field. Most of these concepts were originally formulated by the founders of organized service programs for the blind. The demographic characteristics of the blind population then differed in several important ways from the present population of blind persons. The number of persons in the general population who survived childhood and lived to old age was low, and the number of elderly blind persons was therefore correspondingly small. A major cause of blindness in the adult population at that time was industrial accidents. Ordinarily the eyes were the only organs involved, so that adult blind persons were healthy working people whose only handicap was blindness. Substantial numbers of children were blinded at birth because of diseases that specifically affected the eyes.

Because a majority of the blind in the late nineteenth century were children and adults of working age, the concepts in this field stressed education and employment. Through the years, these concepts have not changed in response to changing social,



economic, and public health conditions. In addition, workers for the blind have implicitly assumed that these problems of education and employment are inherent to the condition of blindness. They have mistaken these concepts for the problem of blindness itself. The blind to whom the concepts cannot be easily applied are viewed by some workers as marginal to the "real work" in the services for the blind. This work is believed to be educational and vocational; services for the elderly, unemployable, or uneducable blind individuals are regarded as marginal activities. Education and employment are viewed as the only alternative solution to the problems of the blind. If a person cannot benefit from either service, his problems are defined as unsolvable, and his case is closed. Consequently, elderly blind persons, the multiply handicapped, and the unemployable are considered apart from the "real problems" of blindness, because some workers for the blind continue to employ archaic concepts in their service approach.

One of the fundamental challenges of this conference lies in a critical reassessment of these traditional, outmoded, reified concepts about the problems of blindness.

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Discussant: Richard A. Kalish

Dr. Scott provides a hard act to follow. I think his only exaggeration was in his need to apologize for what he had not done; I am quite impressed by what he has accomplished. I would like to comment on a couple of thoughts that his paper raised in my mind; and then to move into some areas that reading his paper caused me to consider.

First, a comment about money and the fact that Americans think they can do anything with money. You have noticed jars around to collect money for cystic fibrosis; I observed as I walked by one that an adjacent promotion card stated: ''All we need to cure cystic fibrosis is dollars!" I thought that was a wonderfully optimistic approach, and it fit so beautifully Dr. Scott's point. I am involved now in helping arrange a conference in Los Angeles to determine what program topics older people would like to have presented for their enlightenment, and it might not come as a surprise that one theme they are extremely interested in relates to money. The middle class (and not only the middle class, by the way) come out in large numbers when you offer something on insurance, funeral costs, estate planning, or how to make out wills; and as has been suggested by research, the major variable related to satisfaction with housing is the amount of money one has to obtain housing. As a psychologist, I rather hate to admit that, perhaps, the sociologically-oriented economist might be needed more than psychologists. Thinking about that, I noticed there was no economist at this conference, at least judging from the description of the people given. This often tends to be the case. Very very few people in the field of economics have turned their attention to problems of human aging. The Gerontological Society probably doesn't have more than a dozen-perhaps, two dozen at the outside.

One comment on Dr. Scott's point that the people working with the blind have to readjust their thinking to those individuals who cannot work: I think here we may need to



pay attention to some possible future trends; for example, that it may not merely be older people who will not be working in the world of tomorrow. Right now we are faced with a hard core of unemployment that we are told we are going to have to learn to live with. In the future entry into the work force may be several years later than it is now, the exit from the work force may be several years earlier, and with a guaranteed annual income, a single male of any age, if he chooses not to work, might merely be given \$200 a month. A married man with two children, if he chooses not to work might merely be given \$300 per month. Employers will provide workers with sabbaticals that would permit a man to take off for three months or six months and do what he pleases. We, in our lifetime, I am convinced, are going to have to reevaluate the whole meaning of work, and of those people who need not work. Perhaps the idea that work is honorable and great, and that all Americans have a psychological need to work, may be imposing middle-age values on non-middle-age people. There is a gap here, and I think those of us in psychology and sociology, and perhaps in other fields, have gotten so involved with social class differences that we have completely ignored the fact that an 80-year-old is much different from a 60-year-old, who is much different from a 40-year-old, who is much different from a 20-year-old, although we tend to group all of these people as "adults."

Let me talk now about some of the aspects of aging, particularly those that have special significance for the visually impaired. First, the social relationships of older people are limited. They no longer have the work role. Whether they are anxious to work is not relevant at this point. We know that their relationships tend to be more with neighbors than with people at some distance. I used to live near an elderly couple; the husband was a man well into his 70s, visually impaired, and somewhat auditorily impaired. He was the only man on the street regularly between the hours of nine and five. This is a problem we don't think about when we say older people should be integrated in suburbs with younger people. This man was the only person around. He was terribly lonely, and since I occasionally worked at home, I was sought out as a person with whom he wanted to interact. Social isolation becomes increasingly a problem as sensory impairment of all sorts occurs. Assuming a modest income, a man of this age with good hearing and good vision could, if he wanted to, jump in his car and take off; could, if he wanted to, go with friends to a movie; could, if he wanted to, drive to see his son who lived thirty miles away. Being older makes these social contacts more difficult, being sensorily impaired makes them more difficult, and the interaction of the two makes them, I suspect, geometrically more difficult.

Second is the occurrence of disengagement, a controversial topic in social gerontology. As a result of past experience, some people utilize disengagement in an adaptive manner, while others utilize disengagement in a self-protective or even maladaptive manner. Those who work with older people sometimes give me the feeling that they think anybody who isn't in the middle of things must be, by definition, poorly adjusted. But you can ask yourself to imagine, when you are, say 70, how socially active are you going to want to be? Are you going to want to go out and dance to Lawrence Welk? The pressures against being active, and for becoming disengaged, would seem greater for those elderly who are also sensorily impaired.

Third, older people who are sensorily impaired become more dependent upon others for many things that they do, and for mobility. Living in a town where public transportation is impossibly expensive, or is basically just impossible, as in Los Angeles, a person on a modest income, if he needs to depend upon public transportation, just cannot get around. We find that many older people state as one of their major fears—and this phrase comes up again and again when we talk to older people—"I do not want to be a burden upon my family." So, although the family may live fifteen or twenty minutes way by car, the older person will do many things to avoid even telephoning his

45-year-old child for help. He may, by the way, be somewhat resentful of the fact that he feels this way, too. Here again, blindness would greatly accentuate the fear of being a burden and, perhaps, the resentment as well.

Now, however, I would like to switch, from focusing on the individual, to focusing on the society, with particular attention to those who work with older people. I think we find that those who work with the sensorily impaired place most of their focus on children, and that those who work with the elderly place most of their focus on the healthy elderly, at least on those who can get around. The older, sensorily impaired person falls right in between the slats.

For example, our society places a great value on productivity. How much do you turn out? How many publications do you have? We pride ourselves on this. Even given limitless money, few of us would devote ourselves to a life of pure leisure; participating in what we would consider meaningless leisure would bother us. We emphasize productivity and achievement. I think we also emphasize alertness, although we no longer kill off the elderly, as some subsistence societies did.

Also, we certainly emphasize vigor. This is important. And our society also emphasizes sexual behavior and physical attractiveness: you may look at a photograph of **Isak** Dinesan and say, "She's beautiful," but it doesn't quite stir up the same emotions in you that the face of an attractive starlet might!

We also place a great emphasis on independence. When we address ourselves to a child and say, "You are tied to your Mama's apron strings," it is really one of the most damning things we can say. Yet there are many societies in which the child is literally tied to Mama's apron strings; he may be tied on her back or her side, and Mama goes around doing the housework with baby-san on an apron string.

Also, I think, we are a future-oriented society, rather than a past-oriented society: we focus upon the young. And upon education: we value education, or at least its fruits, tremendously.

All the things I have mentioned are areas and values in which the young have a tremendous edge over older people. We know the increase in educational level of each successive age cohort. Something like 9 percent of the whole population in 1900 were high-school graduates versus something like 60 or 65 percent today. I tried to think of what values might be generated that would give more value to older people. You might want to suggest that of wisdom as against education, stability as opposed to impulsivity. (I thought of Maurice Chevalier's song in Gigi: 'I'm Glad I'm Not Young Anymore.'') The older blind person is even less likely to be productive in society's eyes, to be vigorous, to be independent.

And then, of course, there is something that Dr. Scott also alluded to that occurs when we get to the age when we begin to count years backwards. Then, in appraising a job change, or a marriage change, we begin to ask: 'How many years is this change going to provide fo me?'' If you are thinking of your career and you are 52 years old, you may conclude a career change doesn't really make sense. Leo Simmons, an anthropologist, and others, have indicated that the older person benefits, in terms of community respect and family respect, to the degree that he maintains property control. When he controls property, he is respected. When he does not control property, he is not respected, or not respected so much, although he may be loved more. And today, even if the older person does control property, middle-aged children usually will have enough property of their own that what the older person controls is not sufficient to influence the attitudes of their children. This has come up, recently, in considering



housing for older people; for example, the older couple may own a \$14,000 house that they want to keep to leave to the child who lives in a \$40,000 house of his own. We find that the older person becomes valued less in these ways. The sensorily impaired elderly have an even lower mean income, an even lower standard of living, and therefore less respect and, perhaps, less self-respect.

So we find limits on the value of the older person, on the value of life when the remaining segment is brief. How do we apportion our thoughts, our energies, our time, our money, our grant agency funds? We are told: "Here is a group of children. There are one hundred of them. They are all 6 years old, and statistically speaking they are going to live another 70 years; that is seven hundred years that we are helping or servicing if we help these 6-year-old children." If you talk about helping 60-year-old people, and you want to produce a 700-year service to humanity, you have to have an awful lot of them. The tendency is not to turn to these older people. How do we communicate to people who are steeped in the values of alertness, of independence, of vigor, of achievement, the idea that the dignity of life of an older person is just as important as the dignity of life of a younger person? And how do we communicate the importance of dignity for an older person with major sensory impairment?

We hear a lot of discussion that ours is a youth-oriented society, and I think this is the case. But, I think that this is true because we value things that are found in youth, and therefore that all the propagandizing that we might do becomes irrelevant. One paper given at the recent American Psychological Association meetings, by Lawrence LeShan, discussed psychotherapy for the terminally ill. He was involved in a research and service project in which some 5,000 therapy hours were utilized for such persons. Almost all of these people—I think there were 80 or 100 of them, perhaps more—had died within 12 to 18 months of the end of the study. Many of them, of course, died during the study. Here seems the ultimate challenge, and LeShan put it essentially this way: "If you have a chance to help a person who is going to die in ten minutes, have you wasted your time?" At this end point, we are dealing with the person whose life is probably valued the least. This, philosophically, becomes our ultimate challenge.

Summary of the Scott/Kalish Discussion

Perhaps nowhere in this conference was the difficulty in sorting out the two roles we undertook to fill so hard to disentangle. I speak, of course, of the role of the researcher, pur sang, versus the adviser to program and policy change. Researchers felt themselves entangled in the roles that practitioners play, or else adducing opinions about the roles that practitioners play; while practitioners continually urged the researchers to concern themselves with matters directly related to "needs" and "services"—both of which words are in quotes because it became apparent to both groups that these are accordion words, expanding and contracting as it suited the context and purpose of a particular speaker to use them.

Our chairman apologized for stating the matter crudely when he said that one of the main problems for us to decide is whether the aged blind persons we speak of are more old than blind, more blind than old, or equally blind and old. We might expand this characterization by repeating the complaint of one researcher that we cannot deal with such a huge and heterogeneous population as "the aged blind." For purposes of research, we need a breakdown of this population in terms of social and cultural measures, in terms of groups with similar characteristics; we then need some idea of the tools we have to handle some of these subpopulations (the "hidden blind," and the like), and the kinds of problems faced by aged blind persons

and by practitioners. Without such data, it is not clear what research can be expected to do, or indeed whether the problems faced in these subpopulations are soluble or insoluble.

Complicating both the venue of the researcher and the picture presented by the practitioner are the conflicting conceptions of the population to be dealt with. In part this grows out of the lack of clarity in identifying these populations, as stated above; in part it grows out of traditional definitions of the problems faced by "aged blind," as contrasted with the definitions faced by this population in the language of the opthalmologist, the sociologist, the social worker, the psychologist, and others. Among these varying conceptions were some of the following.

Ours is a youth-oriented culture, as Dr. Kalish pointed out. Or is it? One view of the matter is that this definition of our culture was drawn up by Madison Avenue, and represents the view of a middle-aged society trying to sell goods to the young. Whether or not this is the case, it is of course true that if this definition is believed to be true by a majority of people, certain consequences follow. Among these consequences is the fact that there are no national representatives for the aged, in the same sense that there are representatives of other segments of the society (in spite of one or two organizations based in Washington, D.C., and highly vocal in their advocacy of the interests of retired teachers, retired persons, and so on). What are the implications for research and policy here?

Second, to find out the needs of the elderly blind, it would be wisest not to go through the usual channels, but to use groups like the associations of the retired, to ask the elderly blind what their felt needs are, to assess the self-definition of needs as these persons see them. These self-definitions take on particular relevance vis-á-vis rehabilitation. This is so because rehabilitation implies the taking on of new roles; and one of the most crucial questions one can ask is what new roles are we to have these persons take on. It might be well to keep in mind, however, that such organizations may indeed be so caught up in their own self-seeking that their experience will have little relevance to the problems we are examining.

Third, the direct questioning of elderly blind persons about the needs they have is complicated by at least two factors: the encroachment of senility, and the limitations of their experience. If an elderly person has an idée fixe about his principal interest, he may express no other need than his wish to pursue that interest; this is in part a medicopsychological problem. On the other hand, if he is not senile, but his experience in old age is limited to the rockingchair, he will not express more than the minimum need to permit this constriction of his experience. The first factor may justify a positive response to Dr. Kalish's question about the justifiability of therapy for the aged, at least in human terms. The second factor may encourage the proliferation of some current pilot projects which seek deliberately to expand the experience of older blind persons so that they acquire needs for stimulation and comfort and self-expression. Dr. Kalish would caution us, however, against involving the older person against his will, in the sense that voluntary withdrawal from social activities is perhaps not uncommon among the elderly.

Fourth, the needs of an individual as they are defined by a worker in an agency may be limited by many factors, including the services his agency offers, his conception of the roles that an "ideal client" should fill, and the values the worker defines as important (or which unconsciously guide his behavior choices). One can underscore this matter no better than in Dr. Miller's hilarious example of the blind lady who told a friend that "what they are really doing to me is giving me an appendectomy, though what I need is a hysterectomy. But the thing I most dearly want, most of



all, is a permanent wave." It is not unusual to find a highly competent and independent blind person unable to obtain specific kinds of training (in mobility, for example) because he is unwilling to accept the "package" of services most agencies will insist he take, of which mobility training forms a part.

Fifth, there is already some knowledge we have we could use. For example, we know that it is not always necessary that one should work but rather one should earn money and be independent. Elderly people can accept help if they maintain even pseudoindependence. In this area, the need for the participation of economists oriented toward the problems of old and blind persons was felt to be crucial for the formulation of wise social policy. Furthermore, we can now orient some of our thinking toward the question of what we can do to aid the recipient of services from agencies to negotiate his transactions with the agencies, to manipulate his relationships with them, and to use his capacity to balance the mix of services to meet his needs.

Finally, we should be aware that what knowledge we have may not be adequate or applicable to the problems faced by the elderly blind person. In some respects, we have more knowledge than we need. Moreover, the value judgments we must make, which will tell us what to do, must be made independently, as citizens and not as scientists. There is a danger that our guilt over what was traditionally regarded as the 'needs' of blind and/or elderly persons—needs we now wish to disavow and replace with needs generated partly out of self-definition and partly out of a broadened range of life experience we offer elderly persons—will snare us into remoralizing what the 'needs' of older blind persons 'should' be.

Perhaps our greatest need is to guard against this liability in the role of adviser to social policy formation, and one of the ways we can do so is to enlist the services of research—in assessing "needs" by several techniques, by reviewing critically the programs (pilot and otherwise) set up to meet these needs, and by careful, even rigorous, evaluation of the effectiveness of the programs in meeting their objectives. The greatest pressure on us in all this is the need to make haste slowly; we view the "impending army" of aged blind which Dr. Goldstein has warned us is to come with a heightened awareness of implications for social policy and program planning.

THE PSYCHOLOGICAL IMPLICATIONS OF SEVERE VISUAL IMPAIRMENT IN OLDER PERSONS

Jeanne G. Gilbert

There are stresses attendant upon the process of aging and stresses inherent in the condition of blindness, and when these two are combined within the same person we can expect this person to experience additional stress. How these stresses will be met will be dependent upon the individual himself—his lifelong patterns of living and of reacting to his environment. However, I believe we should differentiate between people who have been blind all their lives and are getting old, and people who are aging and have become blind recently. With those who have been blind all their lives we can expect the normal stresses attendant upon growing old, but there is not the additional stress of blindness because this is something they can be expected to have settled down with, if they are ever going to. However, just the normal stresses of aging are many.

Physically, every person who lives long enough will change. He will change in every organ and in every system, and each individual will be different in his rate of change. Sometimes, in this conference, we have been speaking, it seems to me, as if we separate all people as being old when they reach a certain age, which, of course, is far from the truth. Normal aging is a gradual process which becomes evident in some persons at one age and in others does not appear until much later. Different reactions to these age changes can be expected from persons who have been blind all their lives and from those who hare not. Take the matter of physical appearance, for example: the figure sags, the hair becomes gray or falls out, and wrinkles come. Whether these changes mean the same to a person who can not see them as they might to a person who cannot fail to observe them in a mirror is a moot question. There are some older people who are sighted who spend much time in front of the mirror trying to hide these changes. If the person is a male, he parts his hair farther on the side and puts a few stray hairs over to hide the bald spots. If the person is a woman, she dyes her hair and tries to smooth out the wrinkles with creams. Other older people will just not look in the mirror, this reaction being similar to that of the person who will not go to a doctor to find out what his physical condition is, because if he does not know about it, there can't be anything wrong with him! So, if aging people don't look in the mirror, they don't destroy the self-image they had when they were young and beautiful or young and handsome. Whether this is the same with people who have been blind all their lives, I do not know, but I suspect that there may be some of that same attitude present.

However, other physical changes we can't avoid knowing about, and the ego suffers with the knowledge. We can't run fast; we are subject to more physical disorders; our sexual power wanes; and we don't function as efficiently as we used to.

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These changes nobody can escape, and the declines might be especially important to the aging person who becomes blind because of the consequent impairment of his learning of essential new skills.

The sensory mechanisms change. Possibly these sensory declines too will affect the older person who becomes blind more than the person who has been blind all his life because, when a person becomes blind, he has to learn to utilize his other senses. Now, if hearing and all the other senses have also declined, he has the additional difficulty of learning to make use of these in a constructive way, whereas a person who has been used to doing this all his life can probably continue in his usual way, accommodating to the normal impairment he can expect to experience with advancing age. Intellectual changes also occur if one lives long enough, but the declines are differential. Verbal abilities are pretty well retained, whereas others such as recent memory are lost relatively quickly. Now, when a person has to learn new things and he cannot utilize all his sense, there is an added stress for him. For example, if a blind person's sense of touch has declined it will be harder for him to learn braille, whereas if he had learned braille in childhood, it would be much easier for him to continue using it.

Then there is the matter of social changes. I hesitate to disagree with Dr. Goldfarb, for I admire him and respect his work highly, but I think we cannot discount the fact that there is a stress on youth today. Not only does advertising stress youth, but so also does society, in the matter of retirement. We retire people today at a certain age, regardless of abilities or desires. This is an accent on youth; there are many people who should have been retired at 30 because they have never had a new idea in their lives; while others can function efficiently well into advanced years because they have kept abreast of the times and are full of new ideas. Also, in this era of desegregation, the only truly segregated group I know of are old people: we want to put them in retirement homes or in retirement villages; we want to isolate them from society. My experience with old people indicates they do not all want this treatment. Rejection by society is particularly evident toward a person who is both old and blind, because some older people themselves tend to set their blind peers apart. How the individual reacts to these attitudes depends upon his lifelong pattern of reacting to and coping with stress. The emotional changes that occur in aging are usually more a matter of an intensification of earlier emotional reactions, or a relaxation of earlier, necessary controls of undesirable traits, than actual changes in emotion. A person does not automatically become a sweet old lady, or a benevolent old man, or crotchety, if he hasn't been that way to start with. A person may always have been crotchety and difficult to get along with, but when he was in competition with others he found that it was necessary to hide these traits. When he becomes old, however, he may feel that he no longer has the need to hide undesirable traits, and he gives them full reign. A demanding young person will become increasingly demanding as he grows older. He may have strong dependency needs which become intensified when he has an excuse for them: in older persons, and especially in older blind persons, they are more likely to be accepted.

Both blind and aging people use many defenses to deal with their problems. One of the most common of these is denial. As has been reported here, some blind people deny their blindness. Old people may attempt to deny their aging: they are better than they ever were, they remember better, they can run faster, and so forth—and sometimes die of a heart attack trying to prove it. Others will attempt to rationalize and use aging as an excuse for not doing things they do not want to do. If one has a combination of both aging and blindness it makes a wonderful excuse for many things. He could not possibly do something he does not want to do,

because he is not only old, but blind. It can also be used as a wonderful way of controlling the family. For example, a person who has been in the business or professional world, a person who has been a very important figure, naturally likes to retain this figure or image of himself; if he has nobody to control but members of his family, he will try very hard to control them. Likewise, a woman who has been the pivot around which the household revolves would like to retain her position. Her children have grown up or gone away, but she still wants to hang on to them: "You can't leave me alone now after all I have done for you. Now I'm alone and blind, and you want to leave me." Another show of hositility and bid for control and sympathy may be, "All right, I'll just go to an institution where all the other unwanted people are," which, of course, usually arouses the calculated amount of guilt in her offspring. Another defense in the individual's projection of his own feelings about aging, and his own feelings about blindness. We all grow up with feelings about both. Many have a stereotyped picture of an old person who is discarded, shuffling along, and forgetful. Perhaps they also have a poor image of a blind person. With the combination of the two, the resultant picture may be pretty grim. We tend to attribute these stereotypes to other people who may not feel this way at all.

Many times an older person's isolation is of his own making. If he was a bore all his life, he is probably now an old bore. If he had nothing to talk about except himself and his illnesses, he is probably not now very interesting. If he feels that he is entitled to be rude or demanding because he is old, or because he is blind, he will not be accepted. There are, however, many people who are old, people who are blind, and people who are both old and blind, who accept these things realistically and are still able to be cheerful, interesting, and happy. Adjustment lies within the individual. It does not matter whether one achieves his adjustment by disengagement or by activity; this, I believe, should be his personal preference decision. We workers who deal with old people and with blind people cannot make this decision for anyone. If a person, sighted or blind, wants to grow old sitting and rocking his life away, that is his privilege. If he wants to keep active in life, this he also should have the opportunity to do. We might be able to help the elderly blind person to understand that acceptance by others will depend upon how he, as an individual, makes himself acceptable and interesting to them. There are many people who can and do make themselves interesting, and are accepted and welcomed anywhere, despite their being old, or blind, or old and blind.

Discussant: Monsignor Richard McGuinness

I am sure you have all heard that there are three kinds of lies: lies, damn lies, and statistics. We have discussed statistics, and we heard from Dr. Gilbert about the combination of problems that arise when a person becomes both old and blind. Many statistics we have had in the past are not valid because they failed to isolate factors such as degree of blindness, age at onset of blindness, or cause of blindness. We who work with blind people are well aware of the way these factors influence the acceptance of the blind, the degree of adjustment to the handicap, and so on. I would like to suggest that if we can get more accurate statistics, we will be able to do a better job to help people handle the problems that come to them.

Dr. Gilbert contrasted congenitally blind people and those blinded after age 65. Certainly the age at onset of blindness and the degree of visual loss make a difference in the ability to handle problems. And sometimes there are other handicapping conditions present which aggravate the loss of sight. A severe hearing



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loss, for example, certainly makes the problem of adjustment to blindness worse and creates all sorts of psychological problems.

Another important factor is sex differences. It is a little more acceptable for a woman to be dependent and accept help from others than for a man. Natalie Barraga has shown that degree of vision is not related to the use of reading media. I should say that this is true of travel training also. People who are partially sighted sometimes feel, because of their psychological make-up, much more handicapped than people who are totally blind—and make a much worse "adjustment" than those who become totally blind. So the degree of blindness, and the ability to adjust to a new situation, to accept oneself as a blinded person—all these things have to be taken into consideration if research is going to provide worthwhile answers.

Again, the degree of family support, the ability of the family to come to your aid without making you feel totally dependent on them, the degree to which they help you become independent, the degree to which they help you become mobile—all these things have to be considered. In collecting statistics I think we certainly have to get at such factors as family support. What motivational factors have helped people become adjusted to their new condition, to help them achieve whatever success they have had? We can hope to isolate those factors that have helped people to achieve independence or self acceptance.

We can try to study the conditions that influence the degree of acceptance of blind individuals by society. We have talked very little about public education, and yet each author has mentioned the stereotypes that exist about blindness. How do you break down a prejudice? We can take some lessons from the field of racial prejudices, for it seems that person-to-person contact, meaningful contact, helps to break down prejudice—not just talk, not just public education, not just TV programs, not just reading material, but person-to-person contact in a meaningful way. Maybe the fact that a sighted person learns to give something of himself to a blind person helps him to see some of the problems of the blind person. Maybe it is the fact that he has given something of himself, invested something of himself, learned to value the blind person, which helps him to overcome his prejudices. (Consider the whole matter of volunteer activities in this light.) Maybe it is the need of the blind person himself to make a contribution to the family he lives with, to the society he lives in, to the neighborhood and area he uses, which enables him to be seen in a whole setting as someone who is an influential and valued person. This meaningful, person-to-person contact can be the single best way to help to break down stereotypes about blindness which aggravate the problems of the blind.

The field of public education will be referred to a number of times. I imagine that if we did not have a Vietnam conflict there would be already in existence a guaranteed annual wage for everyone—maybe \$3,000—and everyone would have this guaranteed cellar of income; this would make it acceptable to be at leisure. The whole problem of accepting leisure is important too, and it takes public education to change attitudes concerning it. Early retirement, a later entry into the work force, a shorter work day, periodic sabbitcals—all these things are going to have to be accepted. We can't say simply that we are valuable only because we work. We all have to learn how to accept leisure as part of life.

Another concept I consider important is functional normality. Sometimes people's whole problem is other people's attitudes. Many times a blind person can do the job he did before suffering loss of vision. I have heard of two cases recently in a research study investigating blind persons who were successfully employed (in a factory and a laundry): these blind people both lost their jobs because all of a sudden, the

employer found out they were blind; his attitude was: "... they can't do a job like that, after all that is dangerous." About functional normality, I think public education is necessary to allow the acceptance of blind persons, to allow them the opportunity to show what they can do.

Consider the fact, too, that some of our statistics include a lot of people who may be unjustifiably referred to agencies working with and for blind people. In New Jersey, 15 to 20 percent of the total caseload each year is comprised of people who have more than 20/200 vision—or more than the economic definition of blindness. Yet they are referred because somebody may have a problem, and this is one way of handling it: the one-eyed, or someone who has a moderate degree of visual loss. I think a great deal of this referral has to do with economics. The reasons you have a large number of older persons on the rolls include (1) this is one way of getting a \$600 exemption in income tax; or (2) a certain amount of money will come in, over and above welfare payments (because blind persons have extra expenses); or (3) schooling is wanted. These are some of the reasons people become known to agencies. They need to express their needs to the agencies that can help them. What do they want from the agency? Money, schooling, housing, casework, jobs, employment, and so on. These are the kinds of people we find on our caseload lists, to a much larger extent than people who are already doing pretty well, who don't need help.

It is very hard to isolate the psychological factors that help a person become well adjusted; they are not easily decernible. To deal with people we very often use physical data because they are easier to handle—degree of blindness, the age of person, and so on—and use these to determine eligibility. To determine some arbitrary limit at which people become old, we picked 65; soon it will be 62 or below. When are people to be considered blind? Is it really 20/160, or really 20/200? We know many people who have 20/200 vision who do very well with themselves and don't seem to need any extra help from others. They have enough strength to handle the various problems that come along. Other people who have better vision than this seem to need help. So we use things that are easily determinable by physical data to determine eligibility for various services. We should go along with this approach, but at the same time hope to extract enough extra data that we can begin to do some real research; we need to isolate the factors that help in achievement.

The ordinary problems a blind person faces—loss of mobility, the frustrations of blindness, loss of friend's esteem—are accenuated by the combination of aging and blindness. Is it enough to tell such people to go through the motions, to continue trying to do what they did before and expect that gradually they will be able to do so?

Have we been enough family-centered in our approach to helping people? How much is a social worker required to know beyond his basic skills in order to help a blind person? How much is a psychologist needed? Can we use technicians who are not as well trained as a psychologist to help people adjust to blindness? To what extent can we use home teachers, and to what extent are they unable to help people cope with the problems involved?

How much can one do if a person does not become involved in his total adjustment? A person who is being guided the wrong way has to learn to speak up. "Please don't do it that way. Let's try it this way, it is much easier for me. Thank you very much." It is required that the blind person himself help to educate the general public. I have seen many blind persons do so, and this means a great deal more than seeing something in the newspaper or in an ad on TV or radio. The blind person himself can teach the general public to correct its attitude toward blindness.

The final effort, when we counsel blind persons, is directed toward helping him see all the alternatives open to him. As Dr. Goldfarb questioned; "How do you make people see the alternatives; how do you help them to accept the things that they need." Sometimes we use a wooden, highly structured kind of counseling: "So, you don't want to use a cane; you don't want to use a guide dog—fine. But that means, of course, that you won't be able to get out. You will have to depend on your family and your neighbors, and of course they won't be around all the time. They might be sick sometimes. And if you don't like to use the cane, well, of course, the alternatives now are that when you walk down the street people are liable to think you are drunk, or maybe they are liable to think you are stupid. When you ask the bus driver, 'What bus is this?' he is liable to think you can't read, or you are stupid, or you are drunk, or you are a wise guy."

These are the alternatives we can propose to the blind person. Our goal is to encourage use of the cane by helping the blind person realize the alternatives to not using the cane. So to some extent the burden of helping blind persons become accepted in society rests on the blind persons themselves. We professionals have to help blind persons take the steps that will enable them to get the help they really need. This means listening to them so we can help them express themselves and express needs they have not been able to meet yet in their personal lives.

Summary of the McGuinness/Gilbert Discussion

Service was the dominant keynote of this discussion session. The needs for service, the delivery of services, the adequacy of services, the strategies for change in services—all these played a central role as organizing concepts for the participants.

Yet it is all too easy to fall into a trap during practitioner-oriented discussions of applications of service systems to blindness: it is all to easy to think at an almost idiosyncratic level of abstraction. For this reason, it was urged on practitioners that much can be learned from consideration of the role some current psychosocial variables may play in the structuring of service and the delivery systems set up for rehabilitation. Among these, we would include socioeconomic status; status differences; levels of education; levels of occupational achievement; self-image; prejudice; roles and status; socialization; deviance; stigma; stereotypes; group structure and function; reference groups; autonomy and independence; bureaucratic structure; mobility; and so on. It was generally agreed that by translating discussions of service systems into these terms (or others equally potent), one can help to avoid arguments or analyses that are merely ad hoc, merely rhetorical, and merely self-defensive.

In using these concepts, we can think in terms of four target areas in the population. The first is that contained in the organization system of blindness work, and the system of delivery of treatment (for example, services). The second group is the lay group of the public. The third is the reference group or groups of the blind individual himself. The fourth target is the individual himself.

These conceptual tools are strongly recommended for discussion of the field of the practitioner, mainly because they relp us to get away from the individualized, anecdotal discussion common in this field. Without some perspective, away from the common, first-order level of analysis, we soon find ourselves hopelessly far away from that level of discussion at which we can think efficiently in terms of strategies of change. Without these tools, we often end up merely by saying that "...people need more help, they need more services, we must be more

humane, we must understand the client better," or that we must treat one or another set of particular factors.

Yet our greatest constraints are our limitations in psychic, manpower, and economic resources. The basic question then becomes: "How can we select a strategy of change that has the best potential yield?" And we may choose the variables to maximize or minimize at either the input or the output end of that relationship.

Consider, for example, the application of one traditional tool of rehabilitation to the population of elderly blind persons: education. It is an interesting intellectual exercise to determine what trade-off one can expect by teaching these persons, as part of the rehabilitation or service pattern. And this is a question to be posed after one has answered the even more basic question of the need for special education among the aged blind!

Compounding our difficulties with conceptual tools were some disagreements about the process of aging. Fortunately, some of them lend themselves to resolution through the research process. Here are some examples.

First: retirement is something older people are pushed into by middle-aged people. The popular notion is that the older people resist this pressure; yet the people who might really wish to die with their boots on are likely to be professionals. Most people derive their notions about retirement from what has been achieved during the last thirty or forty years, largely through the efforts of unions. Certainly it is true that people like what work beings them—money, social relationships, and a reduction in psychosocial distance between what they desire and what they have; but do they like work? It should not be difficult to do a study in which we would control for age and disability, and then see whether there is a difference between the retired nondisabled and the younger populations.

Second: housing for the aged. Fifty-year-olds are not pushing 70-year-olds into Sun City. The idea that younger people divorce themselves psychologically from their aged parents may have arisen because there are a number of lonely elderly people who have no children; yet surely there is a sizable number of older persons who are isolated from their children by their own choice. Some research done at UCLA and at USC indicates that people living in retirement communities have a higher frequency, and a larger number, of social relationships than those in nonretirement communities, but there are many reasons why this may be a highly selective process.

Third: on the common observation of the clustering together of sensorily impaired persons. We might hypothesize that this is an "easy way out"; it seems to be a common behavior pattern found in age grading, among the sensorily impaired of several types, all-male and all-female groups, ethnic groups, and many others.

Fourth: the matter of personality changes during aging. We often assume that crotchety old persons are likely to have been crotchety young persons, but is it so? What is the meaning of "adjustment" in this context? It is evident that well-conducted longitudinal studies could settle this question once for all. We know, for example, that certain personality characteristics assist in making the well-adjusted younger person, but a not-well-adjusted, or downright maladjusted, older person; among these would be strong needs for achievement, and the function of vision vs "seeing."

There is obvious need for what some have called "crossdisability" research to help answer questions like these. In fact, except for some peculiar historical circumstances in the field, there is nothing unique in the problems faced in research with the blind-or at least the whole question of uniqueness is a researchable one. We might first seek to understand what is similar, and what is different, among the problems faced by the several disability groups. One intriguing possibility in crossdisability research is the opportunity to join the gap between the discovery of knowledge and its application, to conduct research on how that gap may be joined. One example is to ask how practitioners can teach, train, or educate handicapped persons (regardless of the nature of the handicap or disability) to survive the system of services—to negotiate among agencies to get the particular "mix" of services they want. Some models might actually be found among the group of persons who have successfully negotiated the agency maze. One might also take into account the model mechanism, for national effort, of the heart/stroke/cancer program, and of course the concept of an ombudsman.

The "burning question" in our minds throughout this discussion is the shadow of that army of the aged blind of whose approach Dr. Goldstein has warned us. Because this particular discussion dealt with the problems of the practitioner, it has concentrated on issues of social research; yet we are not unmindful of reducing some of the problems to the biochemical or neurological level; for example, we may well be interested in what are the consequences for kinesthetic and other sensory experience of diminishing vision in the elderly person. We are certainly also aware that, in a medical setting, there are those "successful patients" who have negotiated the complex of medical treatments available to get what they want. Yet there are some consequences of the study of visual impairment by medical practitioners worth considering. It would seem, for example, that (1) it is better to have no vision than to have defective and unstable, or detiorating vision; and (2) it is better to have no vision early in life than to have defective vision at any time. These are, of course, quasiscientific, philosophical statements; yet they have relevance to the delivery system for services. It is possible that there are implications here for impairment difficulties which are "better left alone"? Furthermore, loss of vision in later life may also be associated with brain damage. And there is the matter of postcataract removal psychosis, a condition that is persistent, if not indefinite, in duration.

The matter of brain damage is a serious contender for our attention. In a developing individual, it may result in an eccentricity in walking and/or talking; in a young adult, it may affect reflexes; but in the aged, it may result in complete disability. Does visual impairment act in a similar manner? Among the already impaired, it may be catastrophic; this we know. Then again, it may cause no permanent disarray of personality traits. Consider the impact of blindness or severe visual impairment in a person already deaf: the effect is almost catastrophic. In those already brain damaged, it is cruel in its consequences. Certainly one researchable question becomes: how do we teach anything to these people?

It is evident from the discussion that old age among already blinded persons, and the loss of vision among the old, are two different events; and each requires an appropriate method of study. The differential effects of age on the delivery of services, as a study problem, makes sense in terms of the first group; but it makes little or no sense for the second. We have a variety of populations of this type among the aged blind. Our best bet may be to say that

there are many sources of recruitment to the state of being aged and blind; and that there is a different problem of study associated with each of these sources.

In summary, we should note first of all that the topic of psychological implications among the aged blind, and the associated service delivery systemunder consideration in the last two sets of papers, really—is a delicate one, fraught with difficulties for a joint audience of practitioners and researchers. The conference was, therefore, something of a gamble insofar as it elected to address these questions to such a joint audience. Moreover, we also elected to draw participants from a variety of disciplines and fields. Finally, we elected a topic not previously treated in extenso: geriatric blindness. There is no doubt that a certain amount of our time was spent in generating a common language of discourse (though there are always some who deny that such a language evolved!). Any difficulties in communication may indeed be traced to the wide diversity of background and special languages of the participants. Yet some here will be stimulated to undertake investigations related directly to some of the questions we have raised; some will find similar stimulation from the printed proceedings; some may find that this conference experience will influence their research interests perhaps years from now. We expect, further, that practitioners will wish to consider some of the substantive queries we have raised about the system of delivery of services, and the definitions of needs of the current and the forthcoming populations of geriatric blind; it is highly likely that a conference devoted to their needs will be held soon.

Our most significant result, and particularly so in this discussion session, was to identify the shibboleth of a monolithic population of "aged blind," homogeneous in characteristics. Apart from the two characteristics of age and visual impairment, we soon discovered that a congeries of populations was implied by the category, each requiring a different strategy of discovery.

SERVICE NEEDS OF AGED PERSONS WITH SEVERE VISION IMPAIRMENT OR BLINDNESS

D. C. MacFarland

Any discussion involving the needs of a segment of our population must ultimately describe the population and give pertinent statistics. Without a solid base to work from, it would be difficult to assess the needs and even more difficult to plan service programs to meet these needs. It seems paradoxical that we can be living in a world where machines compute thousands of complex problems a minute and yet we have not been able to count with any degree of precision the number of human beings who are suffering from a disability as severe as blindness. I was pleased to note that a full section of this meeting was devoted to the statistical problem. Therefore, I shall not indulge in the development of any statistical hypothesis and spare you the annoyance of my feeble arguments in support of a set of tenuous figures.

For purposes of discussing service needs for the aging blind, I shall use the most recent estimates published by the National Center for Health Statistics. The persons responsbile for this report would be the first to acknowledge that they have certain inherent weaknesses stemming from the small size of some of the groups included in the sample.

The survey indicates there are 969,000 persons in the United States who are blind or have severe visual limitations (1). This a very conservative estimate indeed when considered against the backdrop of data cited in the recent publication *Ophthalmic Research*: *U.S.A.*, which points up the serious gaps in our current knowledge of ophthalmology and provides us with the significant fact that there are over 90 million persons in the United States who have defective vision (2).

With this in mind, then, we must recognize that we are not talking about a minute segment of the population. Regardless of our knowledge of precise statistics, there is one point upon which every one agrees: more than 50 percent of blindness and severe visual limitation occurs in the age bracket 65 and older. Another facet of the picture is that the aged population is increasing at a more rapid pace today than at any time in history, and this trend can be expected to continue. At present, we have 19 million persons over 65 years in the country (3). By the year 2000 this figure is expected to increase to 30 million.

One phenomenon concerning the aging group is the number of individuals now living beyond age 85. There are 1,124,000 such persons in our nation (4). This trend too will continue, and it has great significance for any plans we might develop for providing services to meet the needs of the older blind or visually limited person. It means that any plan of service must be extended over a period of 20 to 25 years. Too many people today still carry in mind





the old concept of "three score and ten," with the consequence that the programs they devise are stopgap measures, and are at best only meant to assist the older person to live out the few remaining years of his life comfortably.

If I were to presume to cover all the service needs encompassed in my title, I would soon develop this paper into an unwieldy book. Permit me, therefore, to discuss only what I consider essential service needs.

There are five broad basic areas of service needs which I consider essential to full enjoyment of life. These are health care, income maintenance, adequate housing, full social participation, and employment.

HEALTH CARE

Medicaid and Medicare can be expected to remedy some of the gross deficiencies which were painfully evident in health care programs for the aged in the past. Medical experts and social scientists tell us that the number of hospital beds will increase by 50 percent during the next ten years, and there will be a similar increase in nursing home facilities designed to care for the chronically ill. In addition to the obvious benefits of more adequate care for acute and chronic patients, there will be tremendous side benefits accruing from early detection and expert care of cases that might otherwise become catastrophic in nature.

In spite of these fine pieces of legislation, however, it must be apparent to those of us who work with visually disabled persons that good health care alone will not prevent visual disability and blindness. In fact, there are many who hold the theory that good health care, which ultimately results in increased longevity, may also increase the possibility of visual deficiencies. We are not concerned here with this theoretical concept, since the problem is one of recommending services for those who are already blind or who have severe visual impairment.

First, we must make certain that a complete ophthalmological examination is included routinely for all our older citizens and that this examination is repeated on an annual basis. Concurrently with examination, those patients with severe visual loss should be tested for the use of optical aids. Great advances have been made in the field of optics during the past decade, and it is now possible to provide special lenses that can be invaluable for many persons with severe visual limitations. Even though these lenses are expensive, there is no reason why they should not be provided to anyone who can profit by their use, in the same manner that spectacles are given to those without cost in need. Provision of low vision aids, however, will be of little consequence unless trained personnel are available to help the patient understand their use, and to work with him to gain maximum benefit from the prescription.

Because blindness in the older age group is often attended by other debilitating conditions, a thorough physical examination is essential. It seems trite to say that other disabling conditions should be given immediate attention, but all too often the overriding condition of blindness is dealt with, while other disabling conditions may be ignored, thus limiting the patient's future achievements.

A great deal can be accomplished in hospitals and nursing homes through a better understanding of visual disability and some of the simple methods for coping with it. Without going into a list of "do's" and "dont's," suffice to say



that there is a great need for educating hospital personnel in proper methods for dealing with ophthalmological patients. The initial approach to a person who has suffered a severe visual loss is very important in his ultimate total rehabilitation. Extreme ineptness can cause trauma that can leave permanent psychological scars. In nursing homes proper staff training is much more important, because the blind or visually impaired patient may spend the remainder of his life in that facility. The nursing home must be prepared to provide, or have access to, well-trained professional staff who can help the patient achieve maximum independence. This would include mobility instruction for the blind and the near blind; provision of, and training in, the use of optical aids; training in any or all of the activities of daily living; training in special equipment to enable the patient to engage in social gains; and the provision of sufficient reading materials in large print or talking books.

INCOME MAINTENANCE

It is a well-established fact that the blind and visually limited are among the poorest in the country. It is useless to discuss ancillary benefits, even health care, unless we are willing to face the difficult solution of proper income maintenance. At least 25 percent of all severely visually impaired persons in this country are receiving some form of public assistance. If you add to this the number of individuals who are dependent on their families, or whose retirement or social security benefits are inadequate for their needs, the problem assumes pathetic proportions. Some of the persons in the group we are discussing can solve this problem through employment, but for the large majority the only solution is a guaranteed minimum income that is developed realistically in accordance with need, and contains provisions for automatic adjustments to the cost of living. There are many ways of approaching this problem, and perhaps before the ultimate solution is achieved, several methods will be tested. Whatever is done, however, must be done quickly. As I indicated in a paper written four years ago, the people we are discussing here today should be in the forefront of any war on poverty. The need is great and help is long overdue.

ADEQUATE HOUSING

A great deal of national interest has been generated during the past decade in the design and construction of special housing for the handicapped. The genuine concern is evident not only through the efforts of public and private agencies, but also in the opinions voiced by a substantial portion of our citizenry.

My personal experience has been limited to observing the activities of the National Commission on Architectural Barriers. This Commission was created by Congress as part of the 1965 Amendments to the Vocational Rehabilitation Act. It is fascinating to watch the deliberations of this study commission, and to evaluate its penetrating effect on state legislatures and local government. While the main focus of the commission is directed toward making public buildings more accessible to those who are confined to wheelchairs, or may have other mobility problems, the commission has had a far-reaching effect in influencing the design of public housing. Builders are giving serious consideration to the elimination of unnecessary steps, the use of ramps and elevators whenever possible, and the widening of doors to permit free access for those in wheelchairs. The new movement will have a profound effect in the next few years on the extent to which thousands of handicapped persons participate in normal activities and achieve a much greater measure of integration in society—integration which, for the most part, has been denied through

thoughtless planning. It would be very difficult to conceive of anyone wishing to impede this movement. We who have responsibilities for providing services to disabled persons, however, must make certain that programs developed to provide maximum freedom to disabled person do not result in a serious infingement on his rights. I hope you share my concern whenever you hear community leaders talking about special houses for the handicapped, rather than discussing the judicious incorporation of principles that will make all public housing more accessible to the disabled. Every man should have the right to choose where he wishes to live. When this right is curtailed, even as a result of well-intended public sentiment, the outcome is a loss of freedom and an intolerable kind of segregation.

What are the special housing needs for the blind and visually handicapped? The problem here is quite different from that posed for the wheelchair patient. Removal of architectural barriers for the blind person is impossible, for it would mean the removal of all objects, both large and small, that might become obstacles to a blind person's free mobility. For most blind persons, the answer is in instruction in cane technique, or the use of a dog guide, to circumvent obstacles which might otherwise become serious barriers to independent travel. For the partially sighted person, the answer is adequate lighting in all areas of the building and surrounding grounds. Contrary to popular belief, most persons classified as blind have some residual vision-and sufficient light for these persons becomes even more important. Ascending or descending stairs is no problem for the well-trained blind person. In fact, there are only a few architectural features helpful to a blind or severely visually limited person. A few examples are: the standard use of double handrails; avoidance of open stairwells, low balcony rails, doors that open directly to steps, and low hanging objects (such as fire extinguishers, metal signs, and the like). All the foregoing are safety measures a good builder should consider under any circumstances.

To provide maximum independence to persons with severe visual limitations, the structure itself should be placed conveniently near public transportation, but not in an area that carries a heavy load of traffic. If possible, the blind person should give preference to living quarters close to all service areas provided—stores, a central feeding facility, laundry, and other equipment. Living quarters will need no special arrangements other than better-than-average lighting and electric stoves for cooking. (Many visually handicapped people find no difficulty in using a gas range; however, there is an element of risk and, therefore, electricity should be used as often as practical.) The list of changes is very small, but their adoption would provide significant benefits for a visually impaired tenant.

Because titles can be misleading, it is important to reiterate some of the points already alluded to in this section. I should like to make it abundantly clear that those of us who work with blind and visually impaired persons agree that while certain modifications are needed in any public or private housing development, to accommodate a tenant with visual impairment, separate housing is unnecessary and undesirable. Full participation in society is the capstone of all our social action programs soday. This goal, for the older blind and visually handicapped citizen, is attainable, and we should devote our energies to them with this aim in mind. Any attempt to develop segregated housing on the basis of a visual disability would compound the problems and have disastrous effects. A well-adjusted blind person would have no major difficulties living in modern housing units being constructed today. Minor problems which arise are quickly solved if he has easy access to nondisabled friends and neighbors. Denied this help, normally found in any neighborhood, coping with small details can become a real source of annoyance. As professional workers, then, our responsibilities are twofold: First, to make certain the persons we serve are given every opportunity to make a good adjustment to their disability; second, to help the

blind or visually limited person locate in an environment that will permit his maximum integration with society.

FULL SOCIAL PARTICIPATION

Anyone who spends a sufficient amount of time working with the older blind and visually handicapped person recognizes that the most serious problem these disabled individuals face is social isolation.

This problem cannot be dealt with satisfactorily by referral to community recreational organizations, or by membership in golden age clubs, or other channels which are normally considered for the older sighted person. Full enjoyment of leasure time requires an interaction relationship, in which all parties not only receive benefits, but make contributions. For the visually limited, this means an adequate adjustment to the disabling condition, which cannot be accomplished without professional expertise. For many, it will mean mobility instruction so the individual can travel independently. This is especially important in a recreational facility. If the blind person cannot move freely from one area to another, he is really not in a position to pursue activities that are suitable for him and, in fact, he may not even be in a position to choose the individuals with whom he would like to be associated. No one consciously ignores him, but inevitably he is left out of the mainstream of activities, and there is little reason for him to continue the relationship.

Fortunately, many of the games enjoyed by older persons have been adapted for the blind and severely visually limited; however, professional advice is essential to acquaint those in charge so that they can make special equipment available. Obviously, the participant too must be made aware of the broad range of opportunites, and must be given training, when necessary, in the use of specially adapted games and other devices.

Many hobby shop activities—for example, woodworking, metalworking, amateur radio—are ideally suited for blind and visually handicapped persons. However, unless a professionally trained person is available to work with instructors at a recreational facility, the person with a severe visual difficulty may be excluded on the erroneous belief that such a person constitutes a safety hazard to himself and others.

The formidable and frustrating barrier of social isolation can be overcome, but not without a great deal of concentrated effort on the part of professional workers who have this responsibility. Apparently, most communities have the facilities and are willing to share them, but they need our help in showing how this can be accomplished, and in preparing a blind person for his responsibility in the relationship. Our nation is considered one of the most gregarious in the world. We are by nature "joiners," and we have thousands of activities, among which some will suit anyone, regardless of his interest or temperament. With this favorable climate, it would seem that we have failed to develop these resources for the persons we serve. In this short paper, it is virtually impossible to describe even a small number of activities ideally suited for the visually limited, for what we need are not special activities for the blind and visually limited, but an honest effort to make many resources available—and what is more important, to realize that the older person with a severe visual loss needs substantial help in preparing himself to enjoy what is available, without placing undue stress on his friends and neighbors. Our modern society is not yet fully acclimated to long periods of retirement, and even without a disabling condition older people need help in learning how to enjoy themselves. If this is true for the majority, why should it be unusual for a person with a visual loss?



Without meaning to derogate some of the current efforts, I would like to make the plea that segregated facilities be kept to a minimum. Our greatest emphasis must be placed on total social integration into normal society, and only as a last resort or in very specialized circumstances should the development of segregated camps or social clubs be considered.

EMPLOYMENT

Our culture is work oriented, and in spite of automation I suspect it will remain so for a long time. Obviously, the older person with a severe visual loss will be limited in his ability to work. For the majority of these persons, work may be of no consequence. In planning our future programs, however, we must give serious consideration to developing employment opportunities that are feasible for those who wish to work and have the capability.

There are those who feel that an inordinate amount of mor has been spent in preparing, training, and placing blind and visually limited perso. in employment. I cannot share this view. The public and private money expended in this area has proved a prudent investment. I would concede, however, that far too little has been expended in dealing with the critical problems of those for whom employment is not a satisfactory objective.

Published reports from the Vocational Rehabilitation Administration show that more than 13,000 blind and visually handicapped persons were rehabilitated into employment in fiscal 1966. This number has been substantially increased during the current year. Many of the persons employed were above age 45. An organized plan of action is designed to more than double these figures by 1971. A substantial part of the effort will be aimed at developing employment opportunities for the multihandicapped, including the older worker. It is estimated that there will be 6.5 million new jobs in service occupations alone during the next decade. A large number of these jobs will be concerned with providing recreational activities in an expanding economy. (Workers will receive higher pay for shorter hours, and this means they will have both time and money for enjoyment.)

A host of jobs will be available to persons living in rural areas. Many of these will be practical opportunities, on a part-time or full-time basis, for the older visually limited person. Among these occupations are management and rental of lodging facilities, operating game and fishing concessions, boat rental and repair, operating riding stables, bicycle rental facilities, and many others that may require some ingenuity for vocational rehabilitation counselors, but are entirely feasible if the client is interested and wishes to participate. Of course, this is not the major solution for all older citizens with visual disabilities in rural areas, but it does provide opportunities for many who may wish part-time or full-time employment to supplement their incomes.

One proposal under consideration may provide a partial solution for the older blind and visually limited person living in the urban area: the development of unique workshops. Production would be geared specifically to the worker's needs. Work scheduling would be so designed that an employee might work for two hours a day, or for whatever seemed practical, for peak performance. Under these circumstances, the worker could feel justified that he was making his contribution to society, and earn a supplement to retirement benefits. We would suggest that this experiment take maximum advantage of the limited talent now available. The shop could be staffed with older supervisors and managers, because persons drawn from this group would have a much

better understanding of the problems facing the worker, and it is a well-established fact that effective managerial and supervisory talent is available among the retired.

Before closing this section on employment, it is important to emphasize that these projects will serve only a small percentage of the population constituting the main focus of this conference. But if we are to develop a comprehensive plan for meeting service needs, we cannot ignore those for whom employment will be meaningful.

PROVISION OF READING MATERIALS

We have devoted very little time to the use of the large-print books or recorded materials. As a result of the passage of Public Law 89-522, there have been a number of special conferences dealing with the use of reading materials for the blind and visually handicapped. Therefore, this paper would repeat very recent material if it dwelt at length on library services. Needless to say, these are extremely important and should be considered in any service program for the older blind and visually handicapped citizen. Reading is without doubt the greatest single pleasure in which older persons can participate, and much can be done to encourage greater use of library services now available.

Throughout this paper we have discussed service needs from the standpoint of the client, deleting wherever possible specific reference to the personnel required to provide services. We can expect to accomplish very little unless we recognize the important role public and private agencies play in serving the blind and visually impaired. We have referred to total integration into society. For most older persons integration will necessitate extensive counseling and training, and will require the expertise of many disciplines now working with the blind and near-blind. Counselors, social workers, psychologists, mobility instructors, teachers of communcation skills, recreation specialists, and many others must make their professional contributions to enable those we serve to become functioning members of society.

Why should there be special services for this small segment of our population? Do not these special services, in fact, constitute a vested interest that may militate against ultimate integration into society? The group we are concerned with must have special training in certain techniques not available in the usual service organization, and it would not be practical or economical for every organization to have specialists on its staff to serve clients intermittently. We feel that the special agencies for the blind serve a unique role and provide vital links of service that should lead to ultimate integration. There is a tendency on the part of some to work with clients ad infinitum. This is not in the best interest of the visually disabled person, and it reduces severely the number of persons who can and should be served. It is time for all of us to take a hard look to differentiate between the client's needs and those of the agency. Our job is to provide all services required as quickly as possible, to continually encourage community participation, and to terminate the relationship as soon as feasible.

Although we have only been able to touch briefly on the major service needs of blind and visually handicapped persons, it must be quite apparent to all that meeting these needs will require more personnel than is now available in public and private service agencies. The only way we can hope to do the job is through a program involving the expeditious use of trained volunteers. This is especially true with a number of services that are provided for the older blind and visually handicapped person. Such a program, however, must be carefully planned. Recruitment, training, and continuous supervision are of the utmost importance. It is not enough for individuals to want to help; they must be screened to take advantage of their talents, and trained in specific

jobs that are feasible for them. The most important facet of a volunteer program is supervision. The volunteer needs someone to make proper assignments and to ascertain that these assignments are carried out. A supervisor must also make sure volunteers do not become involved in case work, counseling, or other professional disciplines for which they have no professional training. During the past six years, the Vocational Rehabilitation Administration has experimented with the use of volunteers in certain programs, and we find that this is an excellent source for augmenting a small staff. We learned very quickly that it is best to work through a highly organized volunteer organization, such as the Red Cross, leaving the recruitment of personnel to them, and dividing the responsibility for supervision between the volunteer organization and the agency serving the visually limited. A discussion of the employment of volunteers could be the subject of a special paper; we can only note here that properly handled, volunteers constitute a major untapped resource, and should be given priority in future planning.

- 1. Health Interview Survey, July 1, 1963-June 30, 1964. National Center for Health Statistics, U.S. Public Health Service.
- 2. A National Survey Report by T. D. Duane, M.D., Ph.D., initiated and sponsored by Research to Prevent Blindness, Inc. (1965).
- 3. Bureau of the Census, U.S. Department of Commerce.
- 4. Ibid.

Discussant: Irving Miller

Most discussants of papers really write a new paper. That is, they relate their remarks to the paper, but do not necessarily focus specifically on it. I am afraid I want to do much the same, because I want to take this opportunity to express some thoughts and observations about the problem of delivering services to blind people that have concerned me for a long time, and I haven't had an opportunity to present them before; finally, they do emerge from the issues treated in Dr. MacFarland's paper.

I liked Dr. MacFarland's paper, because it is direct and wise. There is little to find fault with in it. It has the uncommon virtue of being concrete in many ways, and of specifying problems and possible services to meet these problems. This is a very good thing, because most often services to blind people are conceptualized by agencies and professionals in broad generalities. This confuses lay people no less that it confuses the professionals. My own preference, which I will not exactly follow here, is to formulate very concrete goals and specific services related to meeting the service needs, and to formulate them in such a way that it is possible to recognize what "doing the right thing" or the relevant thing in service might look like in practice. Broad, vague, and high-minded goals serve as a "cop-out" from the necessity to measure work, to measure performance, and to measure outcomes.

When we consider services to the blind, we must ineluctably or by definition deal with organizations or agencies in the field. Consequently, I want to comment principally on certain aspects of the client-agency confrontation, which I believe have direct implications for research. Dr. MacFarland refers to, or makes observations about, the functions, and in other parts of his paper, about the responsibilities, of the private agency's relationship to the public sector, the division of labor between the agencies, the importance of avoiding duplication and overlapping of services, and so on. Finally,



he caps the discussion by his comment that "It is time for all of us to take a hard look, to differentiate between the client's needs and those of the agency." Let us try to do that.

There are grounds for us to be concerned that, as agencies move along in their organizational careers and become larger, they develop a major stake in organizational maintainence as such, and that they do so at the expense of the purpose for which the agency exists, namely, service to the client. Experience and observation, and innumerable interviews with clients, do suggest very strongly that agencies tend to define client needs by the services they happen to offer, and that clients tend to be individualized into very rigid categories according to the agency's conceptions of what clients need. These conceptions carry the authority, the imprimatur, and the sanction of professional and technical expertise. They ultimately involve political issues, questions, and value choices. and class and special group interests. The interaction between client and agency, the processes through which the client goes in becoming a client, results, in effect, in a special category—a blind person—that is, the agency-type blind person, one who can fit into the style and culture of the agency. Large numbers of the blind, particularly the most deprived, the most socially isolated (and these are among the aged), tend to remain socially isolated and untouched by agency services because they simply don't fit in. From the agency's standpoint they are the 'hard-to-reach' clients. From the client's standpoint, it is a case of a hard-to-reach, or a hard-to-accomodate-to, agency. What actually happens at the point of delivery of service, in my opinion, becomes a critical area for research and study, one which I think some have been interested in pursuing, but about which I think there has been little enthusiasm on the part of agencies.

I refer, for example, to what actually happens to a client in an agency. How is he socialized to the agency? What are the discrepancies between what he sees as the service needs required and what is actually provided? These questions are obscured by professionally oriented preoccupations with concepts of adjustment, personality, family relationships, and emotional reactions to blindness—which often are simply verbal, theoretical explanations, comforting to the worker and assuaging the uncertainties and difficulties he finds in meeting blind clients. These explanations do not necessarily lead to specifically relevant services. They often, as do all generalizations, obscure and dull the edge of attention to specific services related to the present problems of the handicap itself.

In a more general way, what I am saying is that knowledge about a problem doesn't necessarily tell you what you can do about it. The relationship between knowledge-and the kind of knowledge that we have been talking about and thought that we need more of here—and doing is a very puzzling, specialized, and selective type of relationship. In some respects a great deal of knowledge about a problem can inhibit practical efforts to meet the problem. (There is research evidence for that, too.) It is not always true that correct understanding and diagnosis of problems that clients present are required for correct treatment. This discrepancy exists in all professional practice. It is being raised here because I think the failure to recognize the assymetrical connections between knowledge and skill in doing has resulted in insufficient emphasis upon the study of professional practice itself, upon defining and specifying the skill component in practice, of defining the actions and procedures that workers follow to deliver services. I think what we need is some clarification about the relationship and the differences between knowledge and truth-seeking as a scientific pursuit, and knowledge and truth-seeking in professional practice. They operate on different levels of reality, and seek answers to different levels of questions; they seek different orders of knowledge. Professional scholarship and professional research need be concerned with knowledge that can be put to practical use. The other type of

truth-seeking need not have this burden. To be sure, there are relationships between these two levels, and they can support and reinforce each other, but they are not "the same thing." Just as the "right" values and the "right" goals and beliefs do not necessarily lead to an appropriate professional activity, so too knowing "all" about something does not lead necessarily to being able to do something with the knowledge. As you all know, knowing the cause does not provide the cure, as we once believed.

To the extent that we make the assumption that, given the appropriate knowledge, the practitioner will know precisely what to do about it, we simply are not warranted by the realities of experience and by the creative and dynamic aspects of human interaction. If the relationship between research and practice were that one provides the knowledge which the other uses, then we would be in a very sad and impotent state. How does the practitioner keep up with all the research studies that keep pouring out in response to all kinds of problems and needs (including the need to do a dissertation, or the need to get a grant)? And research studies are not often directly related to practice problems in terms of the questions the practitioner must take responsibility to define, search out, and pursue. It is through developing and focusing questions in and about professional practice that we may also achieve a basis for developing clues from, and make selective use of, some of the findings in research that we have been talking about.

Now, to return to some of the themes more directly related to Dr. MacFarland's paper, and perhaps to some questions directly related to services for the aged blind. One of the themes most consistently plucked upon in duscussing service needs is the problem and the undesirability of overlapping and duplicating services, not rationally conceived, for the blind. It appears to be an article of faith amongst us to view with alarm, and regard as a bad thing, the fact that there is competition, duplication, and overlapping in agency services. I think we ought to look at this. I am not for overlapping and duplication, but I think this is mostly a problem for the professional people, for the lay people, for the volunteers, and for the fund-giver, and much less a problem for the client. It is assumed too readily that overlapping and duplication of services is by itself a bad thing. This notion should be examined more carefully than it has been. Whether it is good or bad can depend upon whether we consider it from the client's point of view, or from the agency's point of view. Different interests are involved here. I do not assume, as it is so often comfortably and uncritically assumed, that agency, client, and professional interests are identical with each other; they are characteristically conflictual. To be sure, the points at which the interests overlap are the stuff of which agencies are made, and is what makes it possible to have an agency. But there are also persistent and strong conflicts and differences of interest between the organization, its professional staff, and the clients they wish to serve. Each strives to maintain as much influence and power over each other and the way services are delivered as they possibly can. When, for example, the staff or administration wishes to exert more influence or more power than it has, it is almost always justified on the grounds of public good, higher morality, professional values, or the good of the client. It is bad, of course, when someone has too much of what we want to wrest from him in the first place. The pressure of a staff to democratize an agency, for example, or make it more responsive to the client's needs, is usually really a pressure for the redistribution of power. The accretion of power in one group is always at the expense of another. While the struggle may ostensibly be carried on in behalf of the client, he does not necessarily benefit from it, unless he is able to organize some power, some resources, and some strengths of his own, as he confronts the agency. And, when and as he does so, it will come at the expense of the staff, or the board, or the management. It strikes me, therefore, that the blind client, for reasons inherent to the social situation, as well as in the way the agency's services are organized, is particularly powerless and limited in the ways available to him to exert influence over how, and which, services are rendered. Despite all the efforts, good intentions, good works, and good deeds of most people in the



field of service, the client is characteristically more helpless, more powerless, more dependent than are most other client groups, and their limitations in managing and manipulating their environment are often compounded by the powerlessness to influence those who tro to help them. Reduction of duplication of services tends to centralize power, and makes it easier for services to be controlled by groups further away and less accessible to the client than would otherwise be the case. It may be a good thing, even if unintended, therefore, that clients of agencies for the blind can literally play one agency against the other. While this ability to make choices among agercies—that is, shopping around for services, like they do in large cities such as New York-may complicate the relationship and the nature of the transaction between a worker and a client, it gives the client some unanticipated or unintended influence, some voice, some leverage, and some power of his own. The client may, in the process, achieve some dignity and self-respect, which, though intended, is not the ineluctable consequence of the way agency services are given. One of the implications, which I want to touch upon briefly, is that I believe that organizations of client pressure groups among the blind ought to be fostered, because they hold great possibilities, empirically and theoretically, for influencing and changing the character of services.

Whatever the sins, actual or attributed, of the self-help organizations of the blind, whatever may be the criticisms that have been over the years leveled at them, they have exerted pressure in the direction if improvement. I don't expect the established, traditional agencies for the blind to see virtue in this. These self-help organizations have been a nuisance to the established agencies; they have challenged their hegemony and prerogatives. Individualization of the client, according to his individual needs and situation, is an idea difficult to gainsay. There is evidence, however, that the status of an individual and how he is treated in our society is very much related to the status, power, and influence of his group. This suggests to me that client organizations and client action offer viable possibilities for change in services and service patterns, as well as for maintaining morale, dignity, and a sense of self-worth.

Before going further, and before I get too anxious about this criticism, I want to stress that I do not mean to devalue the importance and values of agency services. They are indispensable, and provide services without which life would be extremely difficult and hazardous for those they do serve. They try to do an extremely difficult task, and mostly do it as well as social realities permit. They cannot be held responsible for the deficits and defects in our social system—for unemployment, for example. It is easy, of course, to criticize them and second-guess them, and I think this is precisely what we should do if for no other reason than to counteract the special immunity from criticism and scrutiny which they seem to enjoy.

Like Dr. MacFarland, I also think it desirable that we strive to develop more precise technologies and greater expertise. It is well for us, however, to take into account that professional technology and expertise, though having the character and aura of neutrality and objectivity, tend to obscure the fact that we are all involved ultimately in political and value choices of various kinds: who shall receive services, what services shall be given, what shall be studied and what shall be researched, and so on. The professional bureaucracy, no less than other bureaucracies, tends to be self-protective. It tries to inhibit access to it by the public, or the various publics, which have an important and primary stake in the services professionals provide. In such circumstances change is difficult to accomplish. I think that these generalizations obviously apply to agencies serving the blind as well. As I have known them, at least in urban centers comparable to New York, they seem to occupy a favorable position, and a seeming immunity from community scrutiny. They tend to be monopolistic, or at least develop a kind of consortium, to control and divide and subdivide service and jurisdiction among themselves. This encourages the risk of sliding by the evidence of large pockets of

need that are not being met, or are difficult to meet, or would require change in the organization to meet. This enjoyment of a special kind of hegemony in the field (except for income maintainence, of course) places the client in the position of not receiving services unless he can get the services from the private agency. The interest of private agencies discourages the expansion of services through development of new agencies, or the expansion of services through the public sector. Any hope that public services would move i to the field to guarantee a minimum of basic services to all blind people, as a right, in the same sense that income maintainence is a legally defined right, would be compromised and complicated by the fact that the private agencies appear to be committed to, and able to sustain, a position approving expansion in the public sector only if the expansion is accomplished through increased subsidies to, and the purchase of services from, the private agencies.

Customs, sentiments, and traditions reinforce the commanding and dominating position of the private agency. Particular patterns of services between the public and the private sectors, and accepted views and ideologies about the respective divisions of responsibility, and about how services should be delivered, raise what seems to me to be a morally challenging issue. There is such an issue insofar as the blind person is completely dependent upon the services of the private agency, which is responsible to its own board of directors, and thus responsible essentially to itself, and is little subject to community question or scrutiny. Private agencies control basic services indispensable to meeting the demands of social living. Blind people must get along and fit into the particular social system of the agency; they have no choice but to do so. If they don't like it, there is no alternative. They do not have, as would be the case with public services, the right to assistance, or even the theoretical alternative of using political methods to influence the character of services. They are subject, without recourse, to the definitions and decisions of essentially private enterprise. My experience and that of others leads to the persistent and nagging feeling that for a variety of historical and social-psychological factors related to certain blind persons, private agencies tend less than others to be encumbered by doubts about the wisdom of their approach and the virtues which they attribute to themselves. They tend more than others to protect themselves and to be protected from criticism. They enjoy much public support and suffer little scrutiny because of the emotionally-laden sentiments (and sentimentalities) associated with blindness. The private nature of these services, and the private responsibilities for such services, are probably directly related to the characteristics of the selective clientele served by these agencies. Specifically, and despite some recent changes about which I have heard, my impression has been that there is little emphasis upon case finding. They rely primarily upon the client taking the initiative to request service. The least adequate and consequently the most distressed, the most dependent, the most hapless and helpless, frequently do not get to use the services of the agency, and I think this is particularly so with the aged, who are usually more socially isolated, less mobile, and so on. Blind people, particularly older blind people, are apt to find it difficult to mobilize their resources and actually get to the agency. On the other hand, I suspect that the more adequate, the more independent, blind person tends to adjure or shun the use of agencies, even if the services provided are needed. Thus, the agency tends to serve a middle group, perhaps an actual minority of blind persons. They serve a group that can adapt, conform, and accommodate to the style or service pattern of the agency, a group with which the agency develops a very interesting symbiotic relationship, a group that can more readily fit into the social system of the agency, a group whose needs and problems are more manageable and fit better the role model of the "good client." The more dependent and needy-the older person-cannot make it to the agency without active help and encouragement. They cannot make it unless others take pains, or are willing to do work that can not be described in fancy, professional language, but it is nonetheless important and basic. Serious consideration ought to be given, therefore, by these and other agencies to special case-finding efforts. 64

Some needs, to be sure, are very complex. We ought not to complicate them more than necessary. Others are relatively simple—for example, the problem of social isolation is real and serious, but is accessible. It is a kind of social isolation that is self-reinforcing: the more the blind are isolated, the more they become isolated, and the more difficult it is to render services to them, and the less able they become to make use of services; consequently, they need direct and practical help and assistance in getting to and from doctors, clinics, social services, and other kinds of services. They need to be followed up, and they need the interest of others. This may help to reduce the resignation and despair so characteristic of blind aged people.

Three matters I want to speak about, specifically mentioned in Dr. MacFarland's paper, are the question of recreation, working with groups of blind people, and the question of volunteers.

Let me be brief. My observation of recreation services for older people, including the blind, is that I would never want to use such a service. Very often they are childish. Often they treat older people like aged children. The playing of games is often really insulting to people, and they often do not really get to the problem. They infantalize people, whereas what they really have to do, in my opinion, is to come to terms with some of the problems that blind people have. They have to try to develop programs—and it can be done, I have seen it done—which will really connect blind people with the community, and make it possible for them to perform and get involved in, social activities which are meaningful to them and not demeaning to them. To verify this description, all you have to do is to visit day center services for aged people, or some of the recreation services for blind people. You will see that they offer very safe and insignificant kinds of services. They don't really come to grips with the adult needs of these people.

I also think that the therapeutic or treatment model that is used has inhibited a concern with the real possibilities of helping people in groups through mutual aid. I think there are real possibilities here, and I have worked with groups of older people and have used professional skill to help clients to use the group in a mutual aid context, to see the group as a mutual aid system in which they actually work on their own problems, and professional skill is used to help them work out their own problems. I think that there are many advantages. When clients work in groups they can allay many of their anxieties in confronting the agency services. They can help clients to actually manage and negotiate the agency better. People need a lot of help in mediating and negotiating the various systems which impinge upon them, and, I have seen the mutual aid group do that. It is a little troublesome; the clients rock the boat a bit. But, if you really want to be concerned with helping people, I think this needs to be explored more than it has. It is also very important that working with clients in groups tends to counteract the powerlessness of clients. I have worked with case workers in several settings who were interested in working with groups, and one of the facts I discovered very quickly was that case workers had a lot of resistance to working with groups, because, frankly, they lose control over communication; the client-worker situation, the individualized situation, is essentially invisible to others. It is one in which the worker has all the models, and the client really can not engage the worker. In the group situation, this is somewhat mitigated, and the worker can not control communication as easily as he can on a one-toone basis.

Finally, a comment on volunteers. Most of us think of volunteers as some kind of lesser professional person, as a necessary evil, as something you would gladly do without if you could afford to. We speak about volunteers augmenting the worker for small staffs, and the like. I think there is another dimension, and another way of conceptualizing their use. I think experience in working with volunteers offers a different type of



relationship to a client. The very fact of not being professional provides values in the relationship that would not otherwise obtain. Clients are really hemmed in by professional functionaries in the community. There is too much of that, and "integrating services and relating the client to a community" is most often thought of in terms of relating him to other functionaries and not the community—not to the bar, not to the church, not to the grocery store, not to other aspects of community life. Relating people to the community has almost always consisted of relating him to the social agency, and keeping him in contact only with professional functionaries. The volunteer has possibilities for another kind of service and help, not just a poor version of what ought to be the professional services provided.

FINAL DISCUSSION

It might well be anticipated that this final discussion provides a vehicle to tie up some loose ends left from the prior discussion sessions. The discussion of the delivery of services, reported above, anticipated some of the argument (but in no way diminished the brilliance of presentation of) Dr. Miller's remarks. Your reporter will therefore opt for the journalistic technique of simple summary, and will reserve some final comment for the conclusion of the discussion.

The question of generation knowledge vis-á-vis the application of knowledge preoccupied us as a genuinely philosophic problem. It becomes apparent from the remarks
made by several participants that when one deals with discrete biological systems, the
chances of a cure, following the demonstration of an etiology, is very high. With more
complicated or more interrelated psychosocial subsystems, etiology becomes far more
complex, and indeed may attain the status of a system itself. One then may legitimately
ask what one can do if one does not know all the determinants of such an "overdetermined"
system. Many persons decide not to act at all, and often this covers up a reluctance
toward unpopular or painful political or social action.

These considerations become particularly relevant in view of the problems in the delivery of services which Dr. Miller treats in his paper. But on the quality of agency service, Miller is at once too harsh and not harsh enough: he has not underscored the terrible discrepancy between the worst practice—which can be medieval—and the best practice, which can be highly effective. It is obvious that in planning for change we should try to eliminate the medieval practices which duplicate one another and overlap in their treatment populations.

To implement this kind of change, one strategy, already suggested, is to permit the client to shop for his services. This is rather a novel concept, and one that would require a study of how it might be done, and also instruction for clients in how to do it. It was suggested, for example, that a systems agency such as the Rand Corporation be engaged to do a war games simulation of negotiating the agencies for optimum match of client need against agency service programs. Not surprisingly, some consideration of this proposal prompted the thought that the most effective changes we can expect or hope to make in the services delivery system are those that occur from within—as happened in the case of the Visiting Nurse Association. Further, we need to give some consideration to a hierarchy of effectiveness for proposed strategies of change, so that we can make intelligent decisions about the greatest trade-off of energy invested in change vs the change produced.

It is in this connection that the modeling of change on the basis of "best practice" agencies may be worth considering. One way of doing this is to insist on the maintenance of high standards of practice, and to accredit agencies offering practice meeting these standards—by controlling the source of funds and insuring they go to best practice organizations. It is imperative, however, that our knowledge be considerably more complete on the nature of the blind population, and on the nature of the services delivery system, before we tie ourselves to a particular model for delivery of services; and so we come full circle to our opening remarks about the need for much more extensive



basic knowledge about the population of blind and severely visually impaired persons, and the persons and agencies who deal with them.

Typical of the wisdom accruing through experience, to be found within this system, is that in planning housing for the geriatric blind, we remember in making plans that these persons are, first of all, old persons, with the generic needs of the aged. We should also remember that, with professional assistance, segregation by the choice of the individual need not necessarily mean social isolation or nonsatisfaction of social needs: ideally, we should be able to provide a range of choices from among which the individual can make his own choice as to his degree of participation in his community.

It is also the case, as experience has shown, that it is the emotionally not the intellectually gifted who work best with the aged; clearly there is need for a selective process to be instituted in recruiting staff.

This wisdom underscores the important point that one of the difficulties of this field of work—work with the blind and severely visually impaired—is that its critics often learn just enough to operate efficiently within it at the point just before they leave the field, or at the point where the routinization of charisma takes its toll of the radical innovator.

However, the problem of inducing change in bureaucratic structures is not unique to the field of blindness—as we have pointed out before. There are no blueprints for such change. One way—and this is a proposal for research—is to initiate evaluation studies of the services that are now offered, whether they are public or private. This is, admittedly, extremely difficult research, but the requirement of public accountability will fall heavily on all of us in our search for change for the better.

In attempting to induce change, one of the basic requirements will of course be personnel. Basic to our understanding of change will be an understanding of the recruitment of personnel to the field, and the elevation of personnel quality, should this be suggested by that understanding. One difficulty in traditional modes of recruitment is the requirement for one-to-one, or face-to-face, service training. This kind of training obviously does not permit us to produce enough people to go around; there is a built-in obsolescence in the training programs. Desperately needed are training programs which manage to increase the number of persons trained for this work, while maintaining the standards for service programs already established in the instances of "best practice" programs. This difficulty may also encourage us to think in terms of the greater utilization of volunteers in metaprofessional roles.

Might we also look to other cultures, and use their wisdom? It does not seem so, judging from the few examples we have considered. To the extent that other cultures face the mounting pressures on their populations from increased urbanization and increased industrialization, then to that extent they seem to face the same problems we have considered in this field. It may be that the experience of other cultures may nevertheless aid us to understand that which cannot be solved, and that which must be coped with after we reach understanding.

In all of this, we proffer just one more caveat to the researcher: the danger of staying too long at the eye of description. There is a danger of reifying our own cultural values, and slavishly implementing them in the programs we propose. It was not suggested, for example, that we make a random selection of agency clients, and subject subgroups out of this sample to different rehabilitation treatments, then test for a variety of characteristics. This kind of procedure we take for granted in basic research, but not in social action research. Even so, we may unknowingly experiment because there



are so many uncertainties in the treatment procedures that very few of us indeed can say, in strict honesty, that we know what we are doing.

To what do all these considerations lead us? It is obvious that we have touched upon only a small number of the range of problems and questions we could have dealt with in this conference. What we can say is that we have identified the need for more information and better planning for the army of aged blind that is now forming. What we have proposed is research to identify the psychosocial characteristics of subpopulations of the nonmonolithic aged blind population; and on the impact, effect, and resultants on social, medical, and other facilities and services provided to visually impaired persons of old age in these subpopulations. We have called for much more fundamental research on blind people, for in truth there is relatively little known about them-there has never been a population study of a representative study of the blind and severely visually impaired, not just those known to and served by agencies for the blind. We have emphasized, further, that only by conducting some fairly large-scale research of this kind will it be possible to answer questions we have raised about the characteristics of the population, and of the subpopulations it contains. And, finally, we have demonstrated that even after such knowledge were to become available, there is still remaining a substantial number of fundamental questions about the services offered to the aged blind, and the context in which they are offered, to afford much scope for both basic and applied research.



A CONCLUDING COMMENT

It is the concensus of the conference staff that its major purposes were accomplished. The group did meet; its deliberations charted, however sketchily, the boundaries of the domain of inquiry to which interest was directed; and a discussion within that context, related both to research and to the practical delivery of services, was initiated. Attention was directed for the first time to a highly important segment of the population of blind and severely visually impaired persons—the geriatic blind—that has received little or no attention in the past.

Mention has been made several times in the discussion summaries of the fact that, since participants were drawn from disciplines both related to the blindness system and from outside that system, there were some difficulties in establishing channels of communication and understanding about the subject area. The description of such difficulties must, in a written abstraction from the rich complexity of actual interchange, distort and magnify them. Indeed, this distortion can be a virtue, and is employed as a didactic technique quite often, as some of the papers presented indicate. There is an important distinction to be drawn, however, between difficulties in establishing what two people are talking about, and the difficulties that arise because they come from different disciplines. The fact that some participants were unfamiliar with the problems of the field of blindness, as a subject area, did result in an exchange of some basic information about blindness; these difficulties are not the ones referred to in the text, for they are quickly disposed of. A common language about the facts and interpretation of the facts about blindness was quickly established among the group members. If difficulties persisted despite that common language, they derived from the unfamiliarity of some of the conceptual models suggested by some of the participants for consideration by others—and it is these difficulties which cause us to think, and hopefully to surpass prior efforts in dealing with the models which guide decision making processes in the field.

As an example of the first importance, let us point out that the group established quite quickly that they were not dealing with a monolithic population of "the aged blind," but rather a heterogeneous population of blind and severely visually impaired people who were aged or elderly, recruited from different backgrounds, and presenting various problems for service programs, for statistical sampling purposes, and for intellectual understanding of their behavior. In the ineluctable battle with these subpopulations, it was inevitable that we became confronted with a wide variety of questions to which only further research, and some further thinking, could provide the answers. This we regard, however, as a successful outcome. Dr. Thomas A. Cutsforth was fond of reminding us that research is successful to the extent that it raised more problems than it set out to solve. In that sense, we have all succeeded mightily.

We look forward now to a second conference to explore the translation into practice of the present and projected research suggested in these papers and discussions, and we are pleased to have had the opportunity to open the discussion about an important, and neglected, portion of our population whose numbers will impose several pressures on us in the very near future.



AGENDA

Research Conference on Geriatric Blindness and Severe Visual Impairment

cosponsored by

The American Foundation for the Blind and Administration on Aging

Mayflower Hotel, Washington, D.C. September 7-8, 1967

Thursday, September 7

9:30 a.m.

Conference convenes

Chairman

Eric Josephson

Presentation Discussant

Hyman Goldstein: "Statistical Implications of the Problem"

Irving D. Goldberg

Discussion Presentation

Robert A. Scott: "The Social and Cultural Context of Aging

in American Society"

Discussant

Richard Kalish

Discussion

12:30-2:00 p.m.

Lunch

Further Discussion

Presentation

Jeanne Gilbert: "The Psychological Implications of Severe

Visual Impairment in Older Persons"

Discussant

Very Reverend Monsignor McGuinness

Discussion

Friday, September 8

9:30 a.m.

Conference convenes

Presentation

Douglas MacFarland: "Service Needs of Aged Persons with

Severe Vision Impairment or Blindness"

Discussant

Irving Miller

Discussion

Summary Discussion

12:30-2 p.m.

Lunch

Further Summary Discussion

Invitees

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Dr. Milton D. Graham (Principal Investigator) Director, Research Department

Miss Zofja Jastrzembska, Assistant Director IRIS

Mr. Robert Lee Robinson (Conference Coordinator)
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Social and Statistical Research Division

Mr. Irvin Schloss Legislative Analyst

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PROPOSED RESEARCH TOPICS FOR THE POPULATION OF THE AGED BLIND

Note: No priorities are assigned to the following in terms of order in the listing or along the dimension of universalistic/particularistic relevancy to the general area of study of the aged blind. Assigning priority is nevertheless regarded as a pressing and immediate need in organizing a national effort in this field.

- 1. What procedures can be developed to minimize postcataract psychosis?
- 2. How can patients with brain syndrome be persuaded to allow diagnosis for corrective lenses, and to use them?
- 3. How can the elderly blind be made to accept hearing aids when a severe hearing loss is present?
- 4. By what strategies does the client manipulate available service delivery systems to get the mix of services that match his individual need? How do we teach him to use these strategies?
- 5. Are there strategies that circumvent the need to restructure service delivery systems—that is, providing free eyeglasses so that examination of the eyes would be performed?
- 6. We need another conference on the delivery of services, involving service personnel and social action personnel; its scope will be defined in part by the content of this conference, but its audience will likely be somewhat larger.
- 7. On the other hand, we may also need another conference on research: to decide the priorities of the suggestions in this listing, and to group some of the ideas expressed in this listing; the end result would be a balanced group of research topics, some parts of which might be taken on as a "package" of research by a research group.
- 8. We need to do evaluative studies of services that are offered to blind persons, whatever the auspices, public or private.
- 9. What effect does the operation of accreditation programs have on delivery systems?
- 10. What is the population of blind and severely visually impaired? What are its characteristics? What is the composition of the several subgroups in this population, by a variety of index characteristics?
- 11. What kind of personnel mix-professional, subprofessional, and nonprofessional—would be most appropriate for the optimum services delivery system?



- 12. What personality characteristics are optimally matched to the three groups of professional, subprofessional, and nonprofessionals mentioned above, and in what areas of service delivery systems are they best utilized?
- 13. We need a survey which asks of the aged blind persons themselves what are their needs and requirements. Data should be analyzed by age, by impairment and/or disabilities present, degree of visual impairment, socioeconomic indices, and others.
- 14. We need some longitudinal studies on the effects of aging (with and without visual impairment) on a variety of characteristics, including activities, desire for isolation, personality changes, and so on.
- 15. To what extent can mutual-aid groups of visually impaired persons themselves be incorporated into best practice delivery systems?
- 16. What best practice system could be set up to deal with elderly blind persons with brain syndrome?
- 17. To what extent can we extract the experience of other cultures, such as that of Japan, in dealing with the aged person with impairments and handicaps?
- 18. Are there new or alternative roles that aged, and aged blind, persons can fill? As counselors, consultants, teachers?
- 19. To what extent are the experiences of other cultures in dealing with the aged impaired influenced by the factors of urbanization and increased technological applications progress—to bring them closer to the set of problems faced in the U.S.?
- 20. Can we identify which of the problems in this listing are not amenable to solution, and thus conserve our energies?
- 21. Would it be possible to do a comparative study of alternative treatment strategies on matched samples of agency clients, in which the treatments given are oriented around the alternative and distinct value systems guiding the several "rehabilitation" pseudophilosophies prevailing?
- 22. What are the prospects for comparative studies of elderly people born blind, elderly people who become blind at different stages in the life cycle, elderly people who became blind gradually, and elderly people who became blind suddenly?
- 23. What longitudinal studies now in progress might be utilized (via additional questions) to provide some of the data on subpopulations called for in this conference?
- 24. What are the prospects for multiservice centers for elderly people handling blind persons; and what patterns of consultation will be most efficient in the use of staff personnel in such centers?
 - 25. What might be the role of an anthropologist in studies of aging and blindness?
- 26. What information can be gleaned from community, or hospital, studies, on the aged blind?
- 27. Are there potentialities in animal reserach—past or present—for answering our questions of the consequences of blindness in advanced age?



- 28. What is the role of the older blind person in his family? A blind grandparent, particularly in three-generation households? In three-generation families of separate residence for the top two generations? Of geographical distance on this relationship?
 - 29. What is the religious behavior and activity of the older blind person?
- 30. What is the possibility of education in modifying the life style of the older, and older blind, person?
- 31. What are the possibilities for developing better information delivery to medical personnel on service systems and procedures?
- 32. We need a survey of the education needs, and the characteristics of the system to serve those needs—or not serve them—for the elderly blind population.
- 33. What are the retention rates among the elderly blind vs the aged without impairment?
- 34. What do the elderly blind need to learn, how long do they learn, what should they learn?
- 35. Can we mount satisfactory programs for primary, secondary, and tertiary prevention of blindness in old age—before we are inundated with the aged blind and our present rehabilitation and service structure?

